Changing the Lens of Stigma:
An Exploration of Disclosure in Self-Portraits by South Africans Living with HIV in the *Through Positive Eyes* Arts Initiative

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature:_____ Date:_____

ABSTRACT

This thesis analyses a collaborative arts initiative, *Through Positive Eyes South Africa*. The thesis focuses on how photography and personal narrative can contribute to changing the lens through which HIV-positive individuals see themselves and the way they are perceived while also problematising the complexities around disclosure and containment in the face of stigma.

There are many projects that have sought to alter the dominant lens of stigma around HIV/AIDS in South Africa but the *Through Positive Eyes* initiative is unique in its process of self-documentation as the group openly confronts the complexities of living with HIV/AIDS. The thesis shows that challenging stigma through art is not as simple as the claim first appears; in fact, it emerges that even in giving full agency to the participants, the boundaries between the private therapeutic process and the public visual encounter are themselves intertwined and blurred by stigma. The thesis analyses the photographs and narratives of six HIV-positive South Africans to explore how their self-portraits contribute to the shift in representation of people living with HIV/AIDS.

The thesis is interdisciplinary in its approach for it draws on texts by critical theorists as well as the work of activists and artists. I also engage with the field of African Studies and draw on the works of Ngũgĩ wa Thiong'o', Steve Biko and Achille Mbembe to analyse the complexities around representations of HIV/AIDS in Africa and the persistence of stigma in the South African context.

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And to all those living today with HIV globally – May the day come where we have equal access to affordable treatment, where stigma is irrelevant and where all human life is valued unconditionally

INTRODUCTION:
INTERWOVEN JOURNEYS

Public Display of a Private Journey

It is the 19th of March 2010, and I find myself waiting in a downtown Johannesburg building at the first display of *Through Positive Eyes South Africa (TPE)*.[1] The clock is counting down as the printer runs into the space with the self-portrait posters fresh off the press. Excitement usurps the anxiety as the seventeen *TPE* members find their individual posters and place them with care around the room. While everyone is so excited to see each other's posters, this also creates the time for each to have his or her own moment to pause and reflect on his or her own photographs and narrative before the public enters this sacred space. Describing the space as sacred is intentional for the participants' private lives are on the brink of being revealed publicly, many for the first time, and this transition has to contain a certain sanctity in the respect that will hopefully be granted to each of them. The bare walls disappear as the focus is drawn to the artists in their bright orange *TPE* t-shirts, and they begin to vibrantly move family, friends, and guests through a journey of living images and personal stories.

To mark the completion of the *TPE* process, honored guest Judge Edwin Cameron distributes commemoration certificates. Both a well-known AIDS activist and Constitutional Court judge, Cameron is the only high-level South African political figure who has disclosed his HIV status publicly. After Cameron's speech in which he refers to the changing political and social climate in South Africa, which now allows for innovative projects like *Through Positive Eyes*, he begins to introduce Mandisa Dlamini.

[1] For access to the most up-to-date information on *Through Positive Eyes*' and to see photographs, film clips, and posters, the website can be found at http://www.throughpositiveeyes.org. [1 February 2012].

Figure 1: *Edwin Cameron and Mandisa Dlamini*[2]

Figure 2: *Late Gugu Dlamini*.[3]

Mandisa is the daughter of the late Gugu Dlamini, but before Cameron's words can even emerge, a sea of orange rises up from their seats and begin to sing "Shoshaloza" – "to go forward or make way for the next man,"

> *Shosholozah*
> *Shosholozah*
> *Ku lezontabah*
> *Stimela siphum' eSouth Africa*
>
> *Go forward*
> *Go forward*
> *on those mountains*
> *train from South Africa*[4]

As if in a pre-choreographed dance piece, they grace their way toward Dlamini and Cameron in one unified movement, their voices overwhelming those of us beholden to the scene… this is the moment. This is what community activist Gugu Dlamini could only imagine when she was so tragically stoned to death after disclosing her positive status on a KZN radio station. Cameron himself wrote in his memoir, "If Gugu could speak out, how could I not?"[5] Over a decade since Dlamini's death, the decision to disclose is still complicated by stigma in South Africa. It has become more accepted over time particularly since 2004 when antiretroviral treatment finally became available in the country, but the tides are still changing and these seventeen self-portraits of

[2] Gordon, Bobby. *Edwin Cameron and Mandisa Dlamini*. 2010. Drama for Life. Web. Available: http://www.dramaforlife.co.za/index.php/gallery/image_full/188/. [1 February 2012]
[3] Artist Unknown. *Late Gugu Dlamini.* nd. Beat It. Web. Available: http://www.beatit.co.za/archive-people/gugu-dlamini. [1 February 2012].
[4] "Shosholoza." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Shosholoza. [24 October 2010]
[5] Cameron, Edwin. *Witness to AIDS.* Cape Town: Tafelberg Publishers Limited, 2005. 59.

the *Through Positive Eyes South Africa* arts initiative are certainly a testament to lives being lived in spite of the persistent challenges and complexities around living with HIV in South Africa today.

Thesis Overview

The HIV/AIDS pandemic has spanned three decades and the global representation of HIV/AIDS has certainly shifted over this thirty-year period. Through a close analysis of the *Through Positive Eyes (TPE) South Africa* arts initiative as my primary case study, I argue that the *TPE* experience contributes to the shift in the representation of HIV/AIDS. *Through Positive Eyes* is a short-term, therapeutic experience for HIV-positive individuals to learn photographic skills and engage with their lives through the lens of a camera, ultimately producing self-portraits fused with their own narrative prose. The first chapter discusses the burden of contesting visual representation of HIV/AIDS that have stigmatised HIV-positive people and how artists, particularly photographers, have the power to transform this burden. The second chapter demonstrates how the *TPE* process is a therapeutic experience, fostering the destigmatisation of the HIV-positive participants through narrative and photography. The third chapter reveals how the metaphor of the 'mirror' repeatedly emerges as a symbol of reflection – self-reflection and the perception of oneself through a particular frame. This metaphor allows me to read how individuals living with HIV/AIDS perceive themselves through the insight provided by photography. In essence, my interest in writing this thesis is to further explore the role of art in the transformation of representations of people living with HIV/AIDS (PLWHA) and to analyse the efficacy and complexity of art as a strategy to combat stigma. I draw on texts by critical theorists in the fields of sociology, anthropology, and visual studies as well as the work of activists to explore the trajectory of the representation of HIV/AIDS and its related stigma. I also engage with the field of African Studies and specifically drawing on themes from the works of Ngũgĩ wa Thiong'o's *Decolonising the Mind: The Politics of Language in African Literature* (1986), Steve Biko's *I Write What I Like*

(1978) and Achille Mbembe's *On the Postcolony* (2001) to analyse the complexities around representations of HIV/AIDS in Africa and the persistence of stigma in the South African context.[6]

Methodology

The primary mode of research for the *TPE* initiative was a form of Participatory Action Research, where project coordinators and the HIV-positive individuals collaborate together from initial discussions through an editing process to a final exhibition. Although the project is not designated a "Photo Voice" project,[7] the concept and process did incorporate some of the key notions of "Photovoice."[8] That "the visual image provides a site of learning" is the premise for the photographic power to transform the photographer and the viewer. Additionally, photographs have the ability to influence policy as these images from *TPE South Africa* will ultimately be taken to the United Nations to confirm the necessity of accessibility and affordability of ARV treatment, individuals themselves are part of the process in creating these images which is the emphasis of *TPE South Africa* and *TPE* in general, and ultimately, when a community of people take action according to their knowledge and their needs, it will have a greater effect on public policy.[9] While this technique was employed for the *TPE* process, this thesis makes reference to my personal

[6] Although the focus of this thesis is on South Africa, representation of Africa as a continent is significant because it is often that the representations of 'Africa' are lumped together regardless of what country or what people they apply to. Many of the concerns for Africa are mirrored across the continent but the distinction between 'Africa,' the continent, and its individual nations and peoples is important, especially when studying the problematisation of HIV/AIDS in Africa.

[7] *Through Positive Eyes* is intentionally not labeled as a 'Photo Voice' project because while it incorporates certain similar concepts, it is not premised on resolving a focused community concern; it's aim is broader.

[8] 'PhotoVoice' is a participatory action research method developed by Carol Wang at the University of Michigan and Mary Ann Burris at University of London's SOAS. This method fuses photography with social issues and community activism allowing community members to take photographs related to community concerns. This is followed by group discussions utilizing the photographs as a launching pad for policy change. For further information, see "Photovoice." *Wikipedia*. [Online] Available: http://en.wikipedia.org/wiki/Photovoice. [1 February 2012] or see Wang, Carol and Burris, Mary. "Empowerment through Photo Novella: Portraits of Participation." *Health Education and Behavior* 21.2 (1994): 171-176. Web. [1 February 2012].

[9] Wang, Carol. "Photovoice: A Participatory Action Research Strategy Applied to Women's Health." *Journal of Women's Health* 8.2 (1999): 186-187. Web. [1 February 2012].

experience and also uses methods of narrative and photo analysis to expand on my research and gain a multifaceted perspective of the complexities involved in an arts-based project aimed to combat stigma around HIV and AIDS. The underlying belief of *TPE* is that one of the most effective methods for combating the epidemic is to challenge the stigma that often exists against people living with HIV/AIDS, specifically using the power of art.[10]

Stigma is defined as the shame or disgrace attached to something (or someone) regarded as socially unacceptable. Fear of association with people infected by HIV is prevalent in South Africa, not because it is inherent in the culture, but because fear is a product of the global social construction that HIV/AIDS is a condition to fear, a condition to escape, a condition linked with death. Fused with its history of racial politics, stigma is deeply embedded in the South African social milieu. In his memoir, Edwin Cameron describes how "the external manifestations find an ally within the minds of many people with HIV and AIDS," and it is this internalised stigma combined with the "prejudiced, bigoted, fearful reactions others have to AIDS" from social stigma that feed off each other in a complex circuitous cycle of stigmatisation.[11] If only we had a common theoretical foundation for understanding stigma, the possibility for coping effectively with its implications would have greater viability within research and interventions.[12] According to HIV/AIDS researcher Harriet Deacon, the development of this perspective on stigma has proved significantly complex, particularly in the study of HIV/AIDS because "it provides evidence of the complex relationships between stigma and existing forms of prejudice, disadvantage, discrimination and the variety of different responses to stigma and discrimination by people living with HIV and AIDS."[13] In this thesis, I analyse an arts-based response to stigma by people living with HIV/AIDS

[10] Gere, David. "About." *Through Positive Eyes*. 2008. [Online] Available: http://throughpositiveeyes.org/about. [1 February 2012].
[11] Cameron, Edwin. *Witness to AIDS*. Cape Town: Tafelberg Publishers Limited, 2005. 53.
[12] Deacon, Harriet. "Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature." *Journal of Community and Applied Social Pscyhology* 16.6 (2006): 418. Web. [1 February 2012].
[13] Deacon, Harriet. "Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature." *Journal of Community and Applied Social Pscyhology* 16.6 (2006): 419. Web. [1 February 2012].

as they create their own self-representations to resist stigma individually and challenge stigma collectively.

My Journey Begins: Revelation of HIV/AIDS

My own journey began nearly twenty years ago when in 1993, I was mesmerized by the words of 'The Real World's Pedro Zamora as he was the first person I heard speak openly about his HIV-Positive status; his point was resolute and oft repeated: "As gay young people, we are marginalised. As young people who are HIV-positive and have AIDS, we are totally written off."[14] This disclosure was a general assessment of perceptions at the time, ten years into the epidemic; and it hit close to home. My cousin Steven had passed away due to a 'disease with no name' and at the time, the questions stopped there. I could not label it then, but this was my first encounter with stigma towards HIV and AIDS. Three years later, I heard about the Names Project and its AIDS quilt founded in 1987.[15] As I saw images of the quilt stretched out across the National Mall in Washington D.C. across the news stations, I recognized the way personal stories could be told visually so that the staggering number of deaths could bring light to the growing epidemic in an artistic way. It was only in 2002 when I joined campus-wide fundraising efforts to benefit AIDS Service Organisations, that I had the opportunity to see actual sections of the quilt at our UCLA Dance Marathon. In the revered space of a room where the quilt hung, there was an opportunity to search names on the quilt. Although I had finally learned that my cousin had succumbed to complications from AIDS, it was in that space that I found the knit section in memory of Steven, completed solely by "Mom", Steven's grandmother.

[14] Zamora, Pedro. *LGBT History Month*. 2011. Web. Available: http://www.lgbthistorymonth.com/pedro-zamora. [1 February 2012]
[15] "About the Quilt." *The Names Project*. 2011. Web. Available: http://www.aidsquilt.org/about.htm. [1 February 2012]

Figure 3: *Memorial to Steve Gilden*.[16]

With the AIDS quilt as a model, while volunteering in Tanzania as a teacher in partnership with the community members where I lived, we organised a patchwork of images designed by students, age nine through twenty, that reflected their thoughts and feelings about HIV/AIDS. After being moved by people's stories of love, loss, and survival through visual testimony in the US and in Tanzania, in 2004, I enrolled in a course titled *Make Art/Stop AIDS* with Professor David Gere. It was in this course that I found my heart's journey as I engaged with local and international artists, all of whom brought HIV and AIDS into the forefront through their respective mediums such as theatre, dance, puppetry, tapestry, muralism, poster art, narrative and photography.

Make Art/Stop AIDS

At the time *Make Art/Stop AIDS* was founded, statistics around HIV/AIDS peaked with 39.4 million people living with HIV, 4.9 million new infections, and 3.1 million deaths.[17] Professor and activist, David Gere, initiated the *Make Art/Stop AIDS* network of scholars, artists, and activists at a workshop held in India. While wearing the "HIV-Positive" t-shirts in solidarity with fellow South

[16] Burman, Marie. *Memorial to Steve Gilden.* c1990s. The Names Project Foundation. Web. Available: http://www.aidsquilt.org/view-the-quilt/search-the-quilt. [1 February 2012].
[17] "AIDS Epidemic Update 2004." *Joint UN Programme on HIV/AIDS.* UNAIDS/WHO, December 2004. [Online] Available: http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2004/2004_epiupdate_en.pdf. [October 2011].

African activists, the group in India discussed and displayed the transformative power of art as a medium through which human rights, gender inequalities, stigma reduction, and treatment access and affordability could be addressed in a unique way.

Figure 4: *Komal Gandhar Dance Group*.[18]

Figure 5: *HIV-Positive T-Shirts in Kolkata*[19]

From a young age I have witnessed the power of art as a tool in education, but my discovery of the way artists' innovation and creativity can influence people's thoughts, perceptions, and even actions materialised through my engagement with *Make Art/Stop AIDS*. Scholar-activist Douglas Crimp writes in his essay "Cultural Analysis/Cultural Activism" that "art does have the power to save lives, and it is this very power that must be recognized, fostered, and supported in every way possible."[20] Crimp's compilation of artist-activist essays in *AIDS: Cultural Analysis/Cultural Activism*, Tracy Kidder's *Mountains Beyond Mountains* on the work of Dr. Paul Farmer in rural Haiti with TB and HIV-positive patients, and Gideon Mendel's *A Broken Landscape*, my first encounter with Mendel's fusion of text and photography, in addition to other informative texts,[21] inspired my journey as an artist-activist in the field of HIV/AIDS.

My specific interest in representations of HIV/AIDS derives from looking more closely at Crimp's compilation of essays. Two of the included articles brought the controversy over the use of

[18] Artist Unknown. *Komal Gandhar Dance Group.* 2004. UCLA Art|Global Health Center.
[19] Artist Unknown. *HIV-Positive T-Shirts in Kolkata.* 2004. UCLA Art|Global Health Center.
[20] Crimp, Douglas. "AIDS: Cultural Analysis/Cultural Activism." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988. 7.
[21] Other influential texts from the *Make Art/Stop AIDS* course include *Combating AIDS: Communication Strategies in Action* by Arvind Singhal and Everett M. Rogers (2003), *How to Make Dances in an Epidemic: Tracking Choreography in the Age of AIDS* by David Gere (2004), *How to Have Theory in an Epidemic* by Paula Treichler (1999), and "The Spectacle of AIDS" by Simon Watney (1987).

the term "victim" to the fore and what image it imposed on 'people living with HIV/AIDS,' a phrase that was developed in response to the "victim" label. Labels and terminology certainly impact on HIV-positive individuals and the way they see themselves; as visual representations shift, the words used to describe HIV-positive individuals must also be scrutinized. Professor-Activist Jan Zita Grover and founding member of the PWA coalition Editor-Activist Max Navarre both examine the term "victim" and how its use denigrates individuals both mentally and physically. Considering the "negative psychological sense" of the word "victim," Grover ascertains the fatalistic implication of the word – that there is nothing that can be done for the "victim" because it is the "victim" who "invited [his] tragedy." In her sardonic tone, she continues to explain how these same "victims"[22] end up being blamed for their powerlessness in an ironic dichotomy of being both the cause and the effect of their own "victimhood". As evidenced, the term "victim" has many connotations attached to it, particularly in the context of HIV/AIDS. Navarre, for example, speaks of the physical impact of the term. As a person living with HIV, Navarre contends, "If we could truly believe in the possibility of *living* with AIDS, I think that the survival figures would be much higher." There is an inherent fear of AIDS that ends up worsening the physical effects of the actual illness as if "they have to be sick even if they're not."[23] This initial foray into the complexities of internalised stigma as a product of globally imposed discrimination remains at the centre of my academic enquiry in this thesis.

Through *Make Art/Stop AIDS*, I have seen first-hand how artists can network to revolutionize the way political and social issues are challenged by bringing together the people on the ground and the 'the powers that be'. The arts can trigger awareness and action in a more unique way than standard information dissemination, and I see South Africa at the forefront of artistic response to HIV/AIDS after my experience with one of the first collaborations between *Make Art/Stop AIDS* and South African artists. In 2006, UCLA was fortunate to have Eunice Mangwane

[22] Grover, Jan Zita. "AIDS: Keywords." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988. 29.
[23] Navarre, Max. "Fighting the Victim Label." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988. 143-44.

join us from Hamburg, South Africa, to present the 4.15 x 6.8 meters "Keiskamma Altarpiece," – a work of art made by 130 rural women, a depiction of hope and redemption in the face of the HIV epidemic in Hamburg. The exchange between Eunice, UCLA and the greater LA community was a huge step forward in humanising HIV by bridging two distinct epidemics of the Eastern Cape province and the city of Los Angeles as Eunice accompanied the altarpiece, speaking on campus and in local churches. The value of this exchange was strengthened by *Flesh and Blood*[24], a performance piece, which reflected on both epidemics in 2007, twenty-five years into the HIV/AIDS pandemic. Through contemporary dance and hip-hop, film, spoken word and music, *Flesh and Blood* educated visiting Los Angeles high school students about Hamburg's epidemic and about the epidemic in LA to compare a global and local perspective of HIV/AIDS and stigma.

Figure 6: *Keiskamma Altarpiece*[25]

The altarpiece opens three-fold as it relays through imagery the stories of loss and the resilience of the community, especially of the grandmothers who often bear the responsibility for their grandchildren in South Africa. This piece was testament to the power one group of determined

[24] For more information on this performance piece and a video clip, see "The Making of Flesh and Blood." *Make Art/Stop AIDS*. [Online] Available: http://www.youtube.com/watch?v=mhAM0uBMVS4. [1 February 2012]

[25] Artist Unknown. *Keiskamma Altarpiece.* C2007. UCLA Art|Global Health Center.

women could have by sharing their story through images. An artistic response to overwhelming feelings of loss and death, "Keiskamma" also uncovered the power of communal resilience in its creation. While some query Keiskamma's validity as a community project because the original idea for Keiskamma, was initiated by Dr. Carol Hofmeyr, a white female doctor and artist whose work is entrenched in the small fishing village, the real significance is that the journey of creation and certainly the final product was indeed a collaboration of efforts by the Hamburg community. This engagement with "Keiskamma" motivated further exploration of enabling visibility of people living with HIV locally and what this 'enabling' meant for the concepts of empowerment and agency. From this Keiskamma exchange, emerged another artist-activist workshop project – "HIV-Positive in Los Angeles" – with the support of South African photographer Gideon Mendel.

Gideon Mendel: From 'Giving Voice' to Empowerment

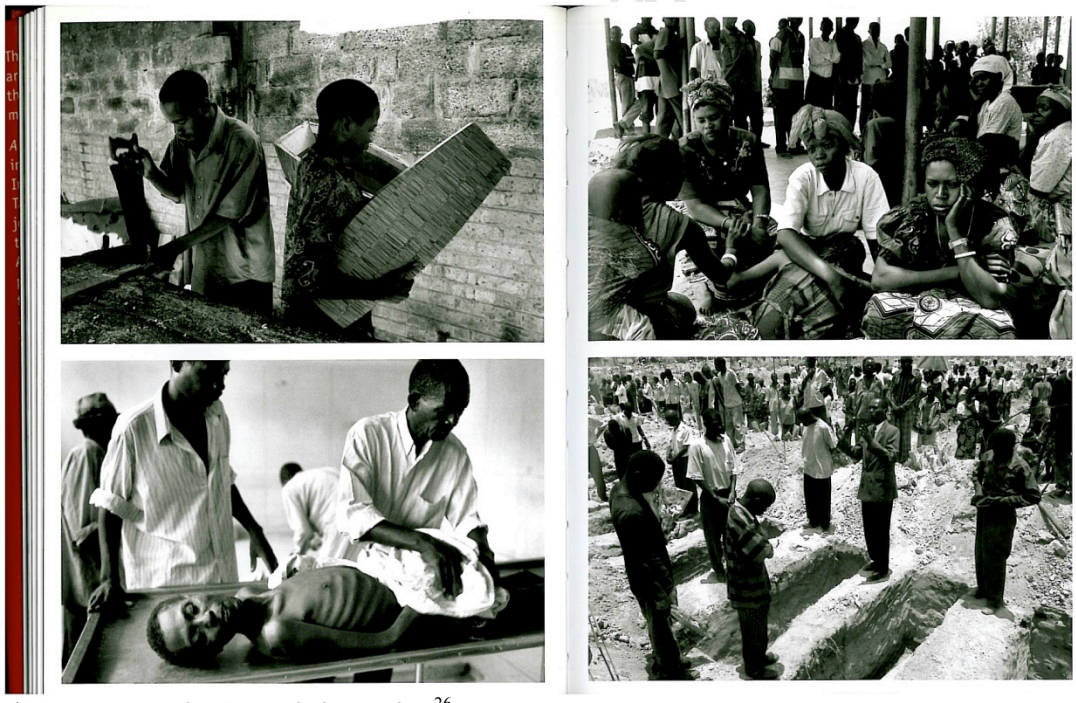

Figure 7: *Funerals, Copperbelt, Zambia.*[26]

[26] Mendel, Gideon. *Funerals, Copperbelt, Zambia*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 94-95.

Figure 8: *Hospitals, KwaZulu-Natal, South Africa*[27]

Through Positive Eyes is the product of a photographic trajectory that precedes it. In order to gain insight into *TPE* as a breakthrough therapeutic arts initiative, I first need to explore the shift in representation of HIV/AIDS in several of Gideon Mendel's works.[28] In *A Broken Landscape*, published in 2001, twenty years into the epidemic, Gideon Mendel documents the state of Africa's 'landscape' of AIDS with images of death and funerals, suffering and loss, tears and pain, orphans and transfer of responsibility to aging grandmothers, but these images stand alongside hopeful images of education and change, care-giving and compassion amidst the devastation. Photographed in Zambia, Tanzania, Uganda, Zimbabwe, Malawi and South Africa, only ten of the 126 photos capture images of laughter, play, and smiling faces – *living* with HIV in Africa at the time was almost irrelevant to the 'landscape' as it was a rarity except for those few who could afford imported drugs. There was only one individual, a woman, Florence Kumunhyu, who was documented with all six respective images breathing with life, showing her as an educator, in her home, and performing.

[27] Mendel, Gideon. *Hospital, KwaZulu-Natal, South Africa*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 48-49.
[28] For more information on photographer Gideon Mendel, see his website - http://www.gideonmendel.com. [1 February 2012].

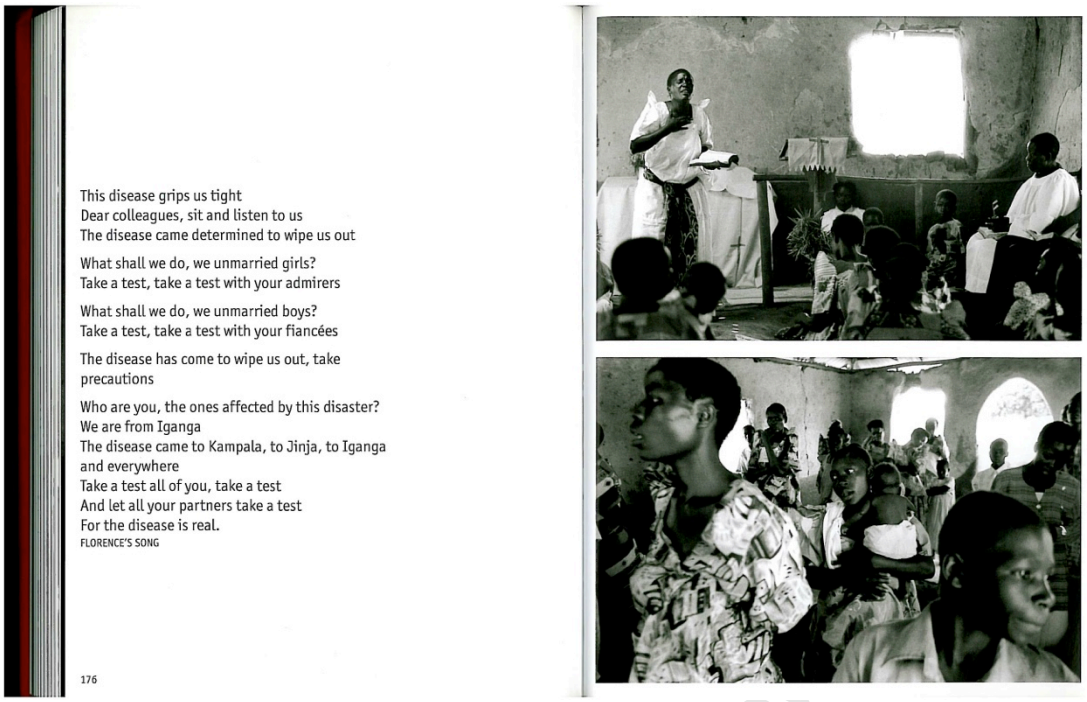

Figure 9: *Florence Kumunhyu, Iganga*, *Uganda*.[29]

Of course, she was in Uganda, one of the few countries on the continent to take a stand against HIV/AIDS almost immediately. In an article reflecting on Mendel's *A Broken Landscape,* art critic Michael Godby writes how Mendel's photographic ingénue "subtly change[s] the image of AIDS in Africa from one of hopeless suffering to one of responsibility and possibility."[30] Mendel exceeded the expectations of the photographic medium "to empower his African subjects" by placing personal narrative alongside images of themselves as we see with "Florence's song" next to the images of her in the classroom. In spite of the inherent photographer-subject imbalance of power, "a problem for documentary photographers at any time,"[31] Mendel actively sought to push the limits of the genre's traditional boundaries particularly in the face of critique.

One critique leveled at disciplines like anthropology, sociology and history is that ethnographers and other types of researchers have assumed the role of imposing a voice on people they consider voiceless. This notion of 'giving voice to the voiceless' is often perceived as a symbol of advancement for marginalised people globally, but 'giving voice' to another also has its

[29] Mendel, Gideon. *Florence Kumunhyu, Iganga, Uganda*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 176-77.
[30] Godby, Michael. "Aesthetics and Activism." *Art South Africa* 5.2 (2007): 3. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].
[31] Godby, Michael. "Aesthetics and Activism." *Art South Africa* 5.2 (2007): 1. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].

hindrances. Having started out as a documentary photographer of the pandemic in Africa, Mendel describes,

> Over time it's become clear to me that my photographs alone can't convey the human reality of the pandemic. These days I travel with both a camera and a recorder so people can tell me in their own words how HIV/AIDS has changed their lives.[32]

While this was certainly a huge step toward transforming the photographic field into recognizing the individual not just a collective perspective, it is with caution that I query the notion that one's 'voice' can be enabled or elicited by another. Seemingly, Mendel's work is a contrast to the recurring images of extreme suffering which "inevitably…are the views of outsiders, well-intentioned in their way, but aimed over the head of their subjects,"[33] without any subject input. Although Mendel transcends the paradigm by including his subject's words in his photographic work, ultimately, the framing lens is still in Mendel's control – in the hands of an "outsider."[34] Why do I query the notion of 'giving voice' 'with caution'? As an academic who sees the significance in oral narrative, on the one hand, I wonder how the narrative of the 'marginalised' individual would get recognized otherwise. On the other hand, it may just be about who does the recognizing? Gayatri Chakravorty Spivak elaborates on this point in a talk she gave on 'The Trajectory of the Subaltern in My Work," where she clearly describes the pitfall of 'outsiders' 'giving voice' to the marginalised, or in her terms, subalterns:

> …attempts from the outside to ameliorate their [the subalterns'] condition by granting collective speech will invariably encounter the following problems: one, a logocentric assumption of cultural solidarity among a heterogeneous people and two, a dependence upon Western intellectuals to 'speak for' the subaltern condition rather than allowing them to speak for themselves…[35]

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[32] Mendel, Gideon. "Living with AIDS." *National Geographic: Africa, Whatever You Thought / Think Again*. September 2005. 68.
[33] Godby, Michael. "Aesthetics and Activism." *Art South Africa* 5.2 (2007): 3. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].
[34] By "outsider," I refer to anyone inherently different from the subject of the photograph either in race, gender, ethnicity, sexuality. I must explain that on the one hand, Mendel is a South African who relates deeply on a cultural level to many of his fellow South Africans but he still con anot intrinsically relate to the internal experience of living with HIV/AIDS as a black African in South Africa or elsewhere on the continent where he photographs.
[35] Spivak, Gayatri Chakravorty. "Gayatri Spivak: The Trajectory of the Subaltern in my Work." *Voices*. University of California, Santa Barbara. September 2004 Lecture. [Humanities – Show ID 8840]. Web. Available: http://www.youtube.com/watch?v=2ZHH4ALRFHw. [1 February 2012].

With the encounter of these two problems, Spivak confirms that no change actually happens to the subaltern who is just re-inscribed in the same subordinate position in society which he/she already holds. By assuming that these 'representative' voices can represent every 'Other', or subaltern, the 'Other' is marginalised once again; the process, although it may be well-intended, fails to empower anyone as it infers one's capability to confer agency on another – "the persistent constitution of Other as the Self's shadow,"[36] re-enforces the dependency of the 'Other' rather than moving into a position to stand independently on his own.

Sean Field, an oral historian and archivist, argues that while this rhetoric of 'giving voice to the voiceless' might appear valuable, it is "misleading and reinforces the 'victim' status,"[37] a label which, as previously discussed, is widely considered demeaning and patronizing. Through my engagement with Gideon Mendel's book, *A Broken Landscape*, from a critical perspective in the *Make Art/Stop AIDS* classroom, I argue that the book 'gives voice to the voiceless.' Although it was certainly not Mendel's intention and there is an obvious urgency for why his images and text address "what is driving this human tragedy and the strength and capacity of the women, men and children coping with unimaginable problems"[38] such as death, loss and suffering, his lens still visibly reflects a Western perception of Africa and all its 'darkness.'

On the other hand, South African cultural theorist and art historian, Anwenn Bates, argues for Mendel's images of the 'skeletal African body' because it is essential to

> …spotlight [the] underlying ideological message: the 'AIDS crisis' is not merely about sick people, but inadequate healthcare systems, societies and governments [and] the [emaciated African] is the tragic embodiment of these inadequacies.[39]

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[36] Spivak, Gayatri Chakravorty. "Can the Subaltern Speak?" *Marxism and the Interpretation of Culture*. Eds. Cary Nelson and Lawrence Grossberg. London: Macmillan, 1988. 24.
[37] Field, Sean. "'What can I do when the interviewee cries?', Oral History Strategies for Containment and Regeneration." *Oral History in Contemporary South Africa*. Ed. Phillip Denis. Durban: Kwazulu-Natal University Press, 2008. 11.
[38] Kaleeba, Noerine. "Introduction." Mendel, Gideon. *A Broken Landscape*. Barcelona: Art Blume with ActionAids, 2001. 10.
[39] Bates, Annwen. "Wearing the T-shirt: an exploration of the ideological underpinnings of visual representations of the African body with HIV or AIDS." *African Journal of AIDS Research* 6.1 (2007): 72.

Therefore Bates' perspective supports Mendel's choice of images in *A Broken Landscape* by explaining that these types of images were necessary to persuade acknowledgement of the crisis effectively. Similarly, Godby agrees that Mendel's images are not intended to portray the African landscape as deficient but as in need of immediate action so that the systems in place can change to benefit the survival of its people. Even though they are few, Mendel's images of smiling, laughter, playfulness, and compassion reveal a glimpse of hope for a better chance at life, a sense of optimism in spite of sickness and death, and his decision to record corresponding narratives confirms Godby's description that Mendel does indeed concern himself with "an evolving subjectivity."[40] In his journey of HIV/AIDS representation, Mendel recognizes the need to push the limits of photography even further so that the images themselves respond to these critiques and transcend them in order to facilitate empowerment. Mendel actualizes the necessity and urgency which Joint UN Programme development advisor on HIV/AIDS, Noerine Kaleeba, concludes to be the most significant aspect of social action against HIV/AIDS –

> …it is vital to be open with people, to share skills, work in partnership, and to make certain that people living with and affected by HIV are at the centre of our responses. We must create an environment which will encourage people living with AIDS to openly seek support and participate in collective action.[41]

It is in this aspect of Mendel's work that *TPE* project director Gere sees innovation. In a reflective exchange with Gere, he describes the empathy Mendel's images in *A Broken Landscape* provoked for him, his colleagues and his students: "Seeing Gideon's images paired with first-person narratives elicited deep feelings of empathy in me, in Robert [Sember], and in our students.[42] For this reason, Gere decided, together with Mendel, to launch a joint endeavor to establish a new way of looking at the epidemic. With HIV-positive individuals at the 'centre of [their] response,' a project about HIV/AIDS in Los Angeles was created to look through a new lens.

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[40] Godby, Michael. "Aesthetics and Activism." *Art South Africa* 5.2 (2007): 4. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].
[41] Kaleeba, Noerine. "Introduction." Mendel, Gideon. *A Broken Landscape*. Barcelona: Art Blume with ActionAids, 2001. 13.
[42] Gere, David. "Gideon and TPE and Photos." Message to Hanni Ress. November 2011. Email.

The First Frame: "HIV-Positive in Los Angeles"

The "HIV-Positive in Los Angeles: Twelve Stories" website introduces the project with a description of the early days of the AIDS epidemic in the US, and how photography was a powerful but controversial tool – "as capable of fomenting stigma as of generating activism,"[43] depending on the frame through which HIV/AIDS was represented. In 2007, Mendel ran a workshop with twenty-four student photographers and journalists; I was one of the journalists. Paired with HIV-positive individuals, the artist-activist teams created photojournalistic pieces around being "HIV-Positive in LA." While we bonded within our own groups, and many of the participating HIV-positive individuals spoke of the experience as 'therapeutic,' 'compassionate,' and 'emotionally releasing,' the feeling of disconnect from the collective effort was impossible to ignore. During the workshop process, there were only two moments where all thirty-six of us shared the same space – at our first meeting where we had a group dinner and at the opening of the final exhibition. While this initial venture was successful on many accounts, particularly as a tool of "visual activism" to be "used to educate and mobilize"[44] on the UCLA campus, it was acknowledged that the absence of interaction between the groups was a huge loss to all involved. For HIV-positive individuals to share their experiences with each other and express their thoughts about the workshop throughout the process would not only have been beneficial for them as individuals but also for the student photographers and journalists. It is through these types of interactions that the participants could have gained more insight into the project as a whole concept rather than fragments scrambling to fit together along the way.

As one of the journalists, I worked with photographer Whitney Fierce, and Pamela Coffey Jr., an HIV-positive woman from Compton. After spending our long weekend with Pam, Fierce

[43] Gere, David and Mendel, Gideon. *HIV-Positive in Los Angeles: Twelve Stories*. Web. Available: http://artsci.ucla.edu/hivla/. February 2007. [1 February 2012].
[44] Mendel, Gideon. In Shana Ting Lipton's "Beyond the Statistics: Student art project at UCLA puts human face on HIV/AIDS." *Los Angeles Sunday Times*, 1 March 2007. E10-E11. [1 February 2012].

and I carefully sifted through her words and the photos taken of her before arranging the final poster. We wanted Pam's words and images to convey the message that she requested of us: "I don't want people to get the wrong perception of me. I'm not just my AIDS."[45] Along with the other eleven individuals, Pam did not want to be seen as just another statistic but as a human being with many dimensions, not just defined by her condition. This became a consistent perspective that filtered through the narratives in this project and later on in *Through Positive Eyes*. While Pam's story reveals her reality in her own words, she, like the others, was still interpreted through the photographic frame of someone else's lens – in Pam's case, Fierce's.

Figure 10: *Pamela Coffey in a Favourite Thinking Spot*.[47]

Figure 11: *Pamela Coffey in her Kitchen.*[46]

With greater interaction between the groups, issues such as 'othering' and agency would have more than likely emerged. Although the HIV-positive individuals played a collaborative role in the early decision-making stages of photographic choice, the subtle 'othering' of the process was highlighted by the more blatant objectification in the *LA Times* write-up where, after some twenty years of

[45] Coffey, Pamela. Personal Interview for *HIV-Positive in Los Angeles: Twelve Stories*. February 2007.
[46] Fierce, Whitney. *Pamela Coffey in a Favourite Thinking Spot*. 2007. UCLA Art|Global Health Center.
[47] Fierce, Whitney. *Pamela Coffey in her Kitchen*. 2007. UCLA Art|Global Health Center.

protest, the people living with HIV/AIDS in LA were once again labeled "victims".

UNGALLERY

Beyond the statistics

An art project that pairs student teams with HIV or AIDS victims puts a human face on the diseases.

By Shana Tiko Lipton
Special to The Times

ABOUT two weeks ago, Whitney Pierce and Hanni Rosenfeld spent a weekend with their new friend Pam Coffey in South-Central Los Angeles. During their three days together they ran errands, got their hair braided and went to a pizzeria. Although this may not sound unusual, for Pierce and Rosenfeld it was a foray into new territory. The former is an art history major at UCLA; the latter an alumnus who works at the university's department of world arts and cultures. Coffey is an African American woman with HIV — a scenario that is becoming more commonplace, as rates of new infection in the United States rise among women of her ethnic group. But Pierce and Rosenfeld are making sure that everybody understands Coffey is not a statistic. They have created a photographic assemblage with words to depict various facets of her life.

The piece is one of a dozen works put together by teams of students and a few nonstudents for an art show on the second floor of UCLA's Glorya Kaufman Hall: "HIV-Positive in Los Angeles: Twelve Stories." Each group paired one writer and one photographer who spent a weekend or slightly longer with a person with HIV or AIDS in L.A. The stories are told in the subjects' own words, through the vision of the project participants — via works that resemble blown-up pages of magazine layouts. Adjacent to each is a professional portrait of the individual, taken by Gideon Mendel, the show's director.

"HIV/AIDS is a huge issue in America that isn't addressed at all," Mendel says. The London-based commercial photographer for publications such as National Geographic has spent 14 years chronicling the disease in Africa. His passion and commitment are exemplified in his book "A Broken Landscape: HIV & AIDS in Africa."

The book was required reading for UCLA's "Make Art/Stop AIDS" course. So it wasn't a leap when its instructor, David Gere — the director of the Art/Global Health Center at UCLA, co-chair of the department of world arts and cultures, and founder of the Make Art/Stop AIDS network of scholars, artists and activists — approached Mendel about the prospect of teaching a class. Mendel proposed something more creative, collaborative and hands-on, and the seed for "HIV-Positive in Los Angeles" was planted. The show, Mendel says, acts as a "tool that can be used to educate and mobilize and make a piece of visual activism."

So it was that Kyla Searle, a metropolitan studies major, and her project partner Lauren Rosa, a world arts and cultures major, spent a weekend getting to know Phill Wilson. He is the executive director of the Black AIDS Institute, an L.A.-based nonprofit policy center, and has had HIV for 25 years and AIDS for 10. The young women accompanied him on routine visits to the hospital, where he had his blood drawn, as well as to a yoga teachers' banquet at which he was honored. The result: their assemblage piece titled "Still Here."

Despite how one might imag-

Whitney Pierce

Pam Coffey: *Diagnosed with HIV two years ago, she will graduate from culinary school this summer. Her goal is to work with women and children affected by the disease. She'd also like to meet poet Maya Angelou.*

Elizabeth Schwoeler

CHRONICLING DISEASE: *Gideon Mendel, left, director of "HIV-Positive in Los Angeles: Twelve Stories," sets up a portrait of Raymond Bowman.*

CALENDAR WEEKEND LOS ANGELES TIMES THURSDAY, MARCH 1, 2007

E10

Beyond the statistics

An art project that pairs student teams with HIV or AIDS victims puts a human face on the diseases.

Figure 12: *Beyond the Statistics*.[48]

Participant and fellow artist-activist Mark[49] immediately remarked to us how regardless of the article's potential inspiration, the domineering title "set us back twenty years." As activist Jan Zita Grover wrote two decades earlier, "it would seem argument enough for dropping the term *victim* that the people called 'AIDS victims' have declared repeatedly that they prefer the designation 'people with AIDS,'" and yet the language still reappears with their "wishes disregarded."[50] This constant mark of powerlessness, a fatal end point,[51] inherently has an impact on one's self-image and one's sense of agency, thereby triggering an internalization of the stigma and discrimination that in a cruel twist, is exactly what many of these individuals are campaigning against. In another faux pas of terminology, in addition to the article's subtitle equating HIV and AIDS with 'diseases',

[48] "Beyond the Statistics." By Shana Tang Liption. *Los Angeles Sunday Times*. 1 March 2007. E10-E11.
[49] I only use the first name here because Mark requested that his surname not be used in any related media.
[50] Grover, Jan Zita. "AIDS: Keywords." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988. 28.
[51] This is in reference to Jan Zita Grover's description of 'fatalism' as one of the problems with utilizing the term 'victim' in her essay "AIDS: Keywords." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988. 29.

one of the photos was captioned 'Chronicling Disease.' HIV is a virus, and AIDS is a syndrome – neither is a 'disease' – but even with two decades of signifying what HIV and AIDS is and is not, the time had not been taken to consider the use of language carefully. Language plays a crucial role in representations of HIV/AIDS according to critical theorist Paula Treichler, for language is

> …one of the most significant ways we know reality, experience it, and articulate it; indeed, language plays a powerful role in producing experience and in certifying that experience as 'authentic'.[52]

Although Treichler refers in her text to language as words and expressions, language can also pertain to a visual vocabulary and how a particular image attempts to portray 'reality'. As the collaborative journey between David Gere's *Make Art/Stop AIDS* and photographer Gideon Mendel continues, it is the campaign to challenge stigma through the language of narrative and photography that makes *Through Positive Eyes* so effective. At the same time, there are several questions that emerge, and it is these questions that form a central part of the argument I aim to make in this thesis: Whose stigma is challenged? Can private stigma be released if public stigma remains? And can public stigma be challenged effectively if private stigma endures?

A New Frame: Through Positive Eyes

Changing the lens of the photographer by incorporating participants' technique and perspective was essential in the transformation from the initial "HIV-positive in Los Angeles" project to the more comprehensive *Through Positive Eyes* arts initiative. In March 2010, seventeen people living with HIV were selected to represent the South African epidemic for *Through Positive Eyes South Africa*. Having learned photographic skills over a ten-day intensive workshop, the participants had authority over capturing their own images rather than their lives being represented by outsiders in the photographic process. Michael Godby praises Mendel's previous works by remarking how "Mendel deliberately abandons the aesthetic criterion on which much of his career as a documentary photographer has been based [so that] control is relinquished to the subjects of his

[52] Treichler, Paula A. "Prologue." *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press, 1999. 4.

portraits and test is prioritized over image."[53] But it is in *Through Positive Eyes* that Mendel's self-restraint as an artist develops into a more tangible reality as he strives to foster the subject's creativity and self-expression. Even in this initiative, while ownership was not completely transferred as the photos and narratives were still under the auspices of the project as a whole, final decisions predominantly remained in the hands of the participants as they created unique photo essays to express their journeys visually as they so chose. The experience of participatory art making in the workshop sets out to create a space to share ideas and thoughts as part of a collective group while also engaging around personal emotions, so that the final display of stories represents both an individual and collective aesthetic. While Gideon Mendel traveled to each of the participants' homes or places of work to photograph their portraits through his lens, the emphasis was always on the images they took themselves. As was displayed at the final ceremony, the stories of participants and their images hold the reins of *Through Positive Eyes*.

While I was absent from Mexico City and Rio de Janeiro, it is important to mention these first two locations to see how the third locale – Johannesburg, South Africa – fits into the global vision of *Through Positive Eyes*. In Mexico City, the project coincided with the International AIDS Conference with its theme, "Universal Action Now," and in Rio de Janeiro, *TPE* engaged in a country that has been at the forefront of treatment access and generic ARV drug production, each country significant in its own way when addressing the respective social inequalities and stigma around HIV/AIDS. To assist the *TPE* team further in identifying and understanding the complexities in different locales, the team joins efforts with a local partner organisation to partake in the process and assist with the public dissemination and sustainability of the final self-portraits. Cross-culturally, the self-portraits reflect the strength gained from ARV access, the hope for longer lives, the desire to be more than a statistic, and the will to survive with all the complexities and

[53] Godby, Michael. "Aesthetics and Activism." *Art South Africa* 5.2 (2007): 5. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].

challenges of living with HIV/AIDS such as traumatic pasts, employment discrimination, and experience with stigma.

Historically, images representing HIV/AIDS told a different story. Cindy Patton describes how "The image of wasting 'African AIDS bodies' fit[ting] neatly into the pre-existing Western image of a wasting *continent* peopled by victim-bodies of illness, poverty, famine…"[54] evokes a visual representation that has dominated the *mis*perception of PLWHA in Africa. By comparing the 'African body' to the 'African landscape,' both become trapped by the compartmentalization of being 'African' – no other qualifiers necessary – reinforcing the recurring stereotypes held in this single description. This global *mis*representation of HIV/AIDS gained concern among AIDS activists in the West who were already involved in changing representations in their own environs. In the early nineties, journalist Simon Watney illustrated the need to transform the predominant image of people living with HIV as "totally isolated, pathetic, silent, hospitalized, dying 'AIDS victims'."[55] Echoing Watney, it is through a shift in image and representation that the circumstances in which HIV-positive individuals' lives will also be transformed, but first Treichler suggests that "filtering devices, a layering of representational elements, narrative voices, and replicating images" need to be considered in order to create a new language of representation.[56] With the subjects' self-representation in photography as a medium of empowering themselves, the photo essays in *Through Positive Eyes* redress a common absence in AIDS advocacy work by invoking the insights of people living with HIV as the central focus of the project. As this thesis shows, while the methodology of utilizing the arts for education and advocacy is effective, combating stigma is a complex objective, not just a factor of the epidemic that can be casually incorporated into an initiative. Stigma is complicated by the reality that internalised and institutionalised stigma are co-dependent and are amplified by the *mis*representation of HIV/AIDS

[54] Patton, Cindy. *Inventing AIDS*. New York and London: Routledge, 1990. 83.
[55] Watney, Simon. "An Introduction." Taking Liberties: AIDS and Cultural Politics. Eds. Erica Carter and Simon Watney. London: Serpents Tale, 1989. 49.
[56] Treichler, Paula A. "Prologue." How to Have Theory in an Epidemic: Cultural Chronicles of AIDS. Durham: Duke University Press, 1999. 108.

in images. For South Africans living with HIV/AIDS, this stigmatised reality is additionally laden with the nation's long history of discrimination and denial.

South Africa: Apartheid to Democracy, AIDS to Denial

> Apartheid conditioned people not to see; when it comes to AIDS many still will not open their eyes.[57]
>
> - Dr. Sam Mhlongo, Professor of Primary Healthcare and Family Medicine at Medical University of South Africa, Pretoria

South Africa has the highest number of people living with HIV in the world with over 5 ½ million infected.[58] This means that of the 33 million people living with HIV globally, nearly 17% live in South Africa. These statistics can only be fathomed with further explanation as to how this burden came to be. Although this thesis does not provide a comprehensive account of South Africa's history of political apartheid, it is essential to discuss some of its devastating effects, particularly in relation to the potency of stigma in the country. Stemming from racial segregation during the colonial era, the system of apartheid was strictly enforced between 1948 and 1994, a system by which individuals were segregated according to their race. The effects of this brutal system continue to affect the post-apartheid context in many ways, particularly in healthcare and education. The economic disparity that exists as a product of colonization, and later the apartheid system, has only widened the gap between rich and poor even further. Access to healthcare, standards of clinics, and availability of medical resources along with educational opportunities are not the same for black South Africans as for white South Africans, even today.

By the early 1990's, then president F.W. De Klerk announced Mandela's release, and in 1994, Mandela won the Presidency under the first completely open, democratic, national election. As the heightened political excitement over Mandela's achievement of victory spread all over Africa, so HIV was spreading itself across the continent's social networks. The stigma that for so

[57] Mhlongo, Dr. Sam. "So, Only African Have Sex?" New African. September 2001. 35. [Found in Julia Stewart's Quotable Africa. London: Penguin Books, 2004. 199.]
[58] "South Africa: Epidemiological Fact Sheet on HIV and AIDS." UN AIDS/WHO. Web. Available: http://apps.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_ZA.pdf. September 2008.

long burdened race in the system of political apartheid that was ending, now replicated itself across races in a new system of medical apartheid[59] that was just beginning. The difficulty in the movement from the political apartheid of the past to the medical apartheid of the present in South Africa is that a group within an already marginalised group becomes further marginalised within their own communities. From a battle of democracy against the apartheid government to a battle of equal access to treatment against the ANC government, South African activists were to face a lengthy challenge. Clearly evident in the controversy over treatment access and availability, the government tolerated the pharmaceutical companies' magnification of the economic gap where generic production was forbidden and monetary value was attached to the worth of a life:

> Like the proponents of apartheid before them, these [pharmaceutical] companies acted to maintain the rules of a system that denies the value of black lives in favor of minority privilege. The result in Africa has been murder by patent.[60]

Indeed, this is quite an extreme statement but considering the time period that it was made, it was still before antiretrovirals were made available at all in South Africa. And this all transpired with the support of government officials who had been the iconic symbols of a new democratic South Africa. While the Truth and Reconciliation Commission was holding court in an attempt to relieve the pain and trauma of the political past, the government in power was simultaneously making decisions that would inevitably incur its 'rainbow nation' with a new type of pain and trauma. In their book, *AIDS: The Challenge for South Africa*, political economists Alan Whiteside and Clem Sunter describe this transition,

> Like a Greek tragedy used to have a cathartic effect on its audience, so the litany of horrors revealed by the TRC was part of the healing process for us. 'Never again' is not a bad message with which to start building a new nation. Yet fate dealt South Africa a cruel blow by replacing apartheid with HIV as public enemy number one.[61]

[59] I use the term 'medical apartheid' in reference to the social disparity in global healthcare systems where social and economic factors hinder adequate health care particularly for the impoverished.
[60] Booker, Salih and Minter, William. "Global Apartheid." *The Nation*. 21 June 2001. 1. Web. Available: http://www.thenation.com/print/article/global-apartheid. [1 February 2012].
[61] Whiteside, Alan and Sunter, Clem. *AIDS: The Challenge for South Africa*. Cape Town: Human & Rousseau and Tafelberg Publishers, 2000. 118.

But the description is considerably more complicated than they accepted. While I agree that both apartheid and HIV were 'cruel blows' to the nation, I disagree that HIV 'replaced' apartheid. Although the system of apartheid was officially ousted in 1994, the repercussions of the system are still blatantly visible more than fifteen years later. The fact that HIV statistics are exponentially higher in the impoverished, predominantly black communities of South Africa is certainly a ramification of the apartheid legacy, a legacy which still affects the nation today. I also disagree with the metaphor equating HIV with being a 'public enemy' because this is the kind of statement that feeds the fuel for stigma to persist. Once HIV is equated with being a 'public enemy,' then so is the individual who is HIV-positive and so it is also evident how even individuals involved in activism can be caught by the trap of stigmatization.

The system through which HIV was handled, or rather not handled, in South Africa was under the same government for whom the nation had rallied, leading them to independence. The colonial system of racial segregation and institutionalisation of inferiority created a skewed power-knowledge relationship[62] in South Africa. Apartheid also created a massive race-based economic disparity, which inevitably impacted on further burdening the social inequalities in the country. Those in power had access to knowledge, and it was obvious that those weakened by the political abuse of mind and body were to have little or no access to new knowledge. This pre-association with whites, the West, power and knowledge obstruction is believed to have played a significant role in Mandela's successor, President Thabo Mbeki' denialist views of HIV/AIDS:

> Mbeki's stubborn opposition to the provision of antiretroviral treatment…was rooted in his belief that Western scientific claims about the origins, causes and spread of HIV/AIDS stemmed from deeply entrenched white racial stereotypes of black Africans.[63]

The same South African political editor, James Myburgh, quoted above, later points out that he reconsidered that Mbeki's support of the alternative 'AIDS cure,' Virodene, was a "necessity for

[62] For more on this power-knowledge relationship, see Michel Foucault's *Power/Knowledge: Selected Interviews and Other Writings 1972-1977* (1980).
[63] Myburgh, James. "In the beginning there was Virodene," Eds. Cullinan, Kerry and Thom, Anso, *The Virus, Vitamins & Vegetables: The South African HIV/AIDS Mystery*. Auckland Park: Jacana Media, 2009. 2.

psychological reasons, 'a medicine developed in Africa for Africa' would racially affirm the new government, and disprove once and for all Western stereotypes of black African incapacity."[64] Despite the problematic and insufficient data to prove its efficacy, Mbeki's support of Virodene was the first of many public displays of his refusal to accept the legitimacy of ARV drugs.

Figure 13: *Virodene, Dr. Rath and HIV*[65]

Paul Farmer cites a Haitian phrase in calling these "stupid deaths," deaths that echo "a great injustice and a stain on the conscience of modern medicine and science,"[66] not to mention the conscience of humanity. Even though antiretrovirals, even today, are not a cure, they work to slow the progress of the virus enough to extend living years considerably.

It was only in 2004, after years of campaigning by the South African AIDS activist movement Treatment Action Campaign (TAC) and associated organisations, that the government finally approved the availability of free ARV drugs to those with CD4 counts below 200 and in 2005, the rollout began. Over a period of 5 years, the number of South Africans receiving ARV

[64] Myburgh, James. "In the beginning there was Virodene," Eds. Cullinan, Kerry and Thom, Anso, *The Virus, Vitamins & Vegetables: The South African HIV/AIDS Mystery*. Auckland Park: Jacana Media, 2009. 4.
[65] Shapiro, Jonathan (aka Zapiro). *Virodene, Dr. Rath and HIV*. Cartoon. *Not Alone* Catalogue. Web. Available: http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf. [1 February 2012].
[66] Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berekeley: University of California Press, 2005. 144.

treatment has increased from an estimated 55,000 in 2005 to reaching nearly 1 million in 2010.[67] Even though only about 18% of those infected are receiving ARV treatment, South Africa currently has the largest public sector ARV programme, and this in itself is an amazing success considering the nation's long haul to arrive at this juncture. South Africa's political and social history is inherently part of the fabric of the nation that exists today. It is necessary to include this contextualisation as the transformation in South Africa, particularly in its management of HIV/AIDS treatment access and affordability, is crucial to understanding the stories of all South Africans living with HIV/AIDS.

Changing the Lens of Stigma: Resistance and Resilience

While *Through Positive Eyes South Africa*'s private therapeutic process and public visual encounter certainly contribute to changing the lens of stigma through which HIV-positive individuals see themselves and the way they are perceived by others, this thesis problematizes the complexities around disclosure and containment in the face of stigma. In Chapter One, I argue that the burden of representation of HIV/AIDS and particularly HIV/AIDS in Africa is heavily dependent on the art of photography. The only way for the visual vocabulary to change is through a transformation in the photographic lens so that new images of HIV/AIDS can reveal themselves. Art has the potential for being a tool of resistance and change; but it is the artist's responsibility to inspire a shift in representation. In Chapter Two, I argue that the *Through Positive Eyes* arts initiative is a model case study to demonstrate how photography serves as a tool, not just of transformation, but of destigmatisation for an HIV-positive individual. *TPE* casts this process of destigmatisation as a journey through which all people living with HIV/AIDS must travel in order to find acceptance. In Chapter Three, I argue that the emerging symbolism in the metaphor of the 'mirror' reflected in several self-portraits also contributes to the shift in representation of people

[67] South Africa: Treatment and Care." UNSource: Country Progress. Web. Available: http://www.unaids.org/en/regionscountries/countries/southafrica/. 2010.
Reports submitted to UNAIDS in 2010 for the UNGASS reporting process. Data reflect latest available country data reported in 2010, but period of data collection may vary.

living with HIV/AIDS. Through an analysis of one's self-encounter and the encounter of self by others, I explore the influence of the global mirror and the individual mirror through the self-portrait. Throughout all three chapters, I recognize art as a strategy to combat stigma, but I also assert that the extent of the transformation must be examined more closely. It is evident that challenging stigma through art is not as simple as the claim first appears; in fact, it emerges that even in giving full agency to the participants, the boundaries between the private and the public are themselves blurred by stigma. In conclusion, I explore the artistic approach in conjunction with new strategies to combat the complexities of stigma, in respect to my thesis argument, through an in-depth analysis of several *Through Positive Eyes'* self-portraits.

CHAPTER ONE:
THE VISUAL BURDEN OF HIV/AIDS REPRESENTATION

> Good pictures. Tragedy and violence certainly make powerful images. It is what we get paid for. But there is a price extracted with every such frame: some of the emotion, the vulnerability, the empathy that makes us human, is lost every time the shutter is released.[68]
>
> - Greg Marinovich, South African photographer

> The meaning of the photographic image is built up by an interaction of such [learned] schemas or codes… The image is therefore to be seen as a composite of signs… Its meanings are multiple, concrete and, most important, *constructed*…[69]
>
> - John Tagg

The tree is my body and the nests is the virus that is in me. Even though I do have the virus, I can live as green as the tree even if I do have the virus. I think that is why I took that picture. I really love that picture.

- Gladys

Figure 14: *Trees and Nests*

Art has the potential for being a tool of resistance, but it is the artist's responsibility to inspire this social and moral activism. The transformation of an individual or of a society through creative channels is an aspiration for artists who want to contribute to shifting social perception. There is an undeniable burden on these artists who strive to represent something or someone in a particular light for it is their artistic choices that can determine how that something or someone will be perceived then and thereafter. Or do they? There must also be some responsibility on the part of the witness to the image and the way the image is perceived. Art critic and artist John Berger draws light to the significance of an image and its multi-faceted associations:

> Every image embodies a way of seeing. […] Every time we look at a photograph, we are aware, however slightly, of the photographer selecting that sight from an infinity of other possible sights. […] The photographer's way of seeing is reflected in his choice of subject.

[68] Marinovich, Greg and Silva, Joao. *The Bang-Bang Club: Snapshots from a Hidden War*. London: Arrow Books, 2000. 194.
[69] Tagg, John. *The Burden of Representation: Essays on Photographies and Histories*. London: The Macmillan Press, 1988. 187.

> Yet, although every image embodies a way of seeing, our perception or appreciation of an image depends also upon our way of seeing."[70]

Therefore, while representation in photography is primarily in the hands of the photographer, it is also dependent on the 'eye of the beholder'. Transformation through creative expression is the essence of the *Through Positive Eyes* workshop experience for the group shares parts of themselves through a fusion of narrative and photographs.

In this chapter, I explore three key themes: the significance of the group dynamic and the space as a crucial factor in framing the *Through Positive Eyes* therapeutic process, the power of art as a tool of resistance and transformation particularly in the South African context, and the role of photography in the representation of HIV/AIDS and its effect on visual vocabulary particularly regarding 'Africa' and 'Africans.'[71] The seventeen HIV-positive individuals of *TPE* assume the artistic 'burden of representation' in the construction of their own self-portraits, but in this chapter I will focus on one of them – Gugu Dlamini[72]. There has been a significant complexity concerning the representation of HIV/AIDS, particularly in Africa, but with the presence of creative outlets such as *TPE*, the paradigm is shifting as the represented become the representers and the photographed become the photographers.

The Healing Process: A Prerequisite for Resistance

> Healing yourself is connected to healing with others.
> - Yoko Ono

Upon arriving at Arts on Main on Day One of the project, a team of twenty-six strangers – local and foreign, black and white, male and female, gay and straight, Christian, Rastafarian, Buddhist, Atheist and Jewish, South African, Zambian, British and American – and certainly plenty

[70] Berger, John. *Ways of Seeing*. London: Penguin Books, 2008. 2-3. (First Edition 1972).
[71] I place inverted commas around both of these terms because they are problematized by the way they are often used. Irrespective of the place or people one is speaking about on the continent, it is often lumped into 'Africa' or 'Africans', symbolic of how Said's 'Other' is homogenized as such. To read further, see Edward Said's *Orientalism* (1979) and V. Y. Mudimbe's *The Invention of Africa* (1988).
[72] Age 30, Living with HIV for 16 years, 754 Photographs – Also to clarify, this participant shares the exact same name as the slain community activist but there is no relation. They are two different Gugu Dlaminis but the participant is certainly following strongly in activist Gugu's footsteps.

more loaded dichotomies that could be included – joined together to partake in a creative healing process. This process had already begun for many of the participants but in healing, it is usually an ongoing process without a definitive end. Through art, memories and images that may have been repressed can be re-created visually and the individual is given the opportunity to share the significance of these images with the group. Therefore, *TPE* teaches creative strategies with new visual tools to inspire internal resilience and facilitate the capacity to resist the externalized visual burden. The dynamic differs when the journey of healing is shared as part of a group. Although individual journeys happen, one can learn from his/her peers' journeys as well. Particularly for people coping with a similar struggle, the individual process benefits from the group process. Sharing testimonies and life experiences can be mutually advantageous in overcoming stigma as it encourages active involvement. Individually and communally, art can act as testimony to social and political reality, and it is essential that the lives *lived* in the midst of these particular revolutions in time be recognised. In his *Ways of Seeing*, John Berger describes the value of an image in the sharing of history,

> No other kind of relic or text from the past can offer such a direct testimony about the world which surrounded other people at other times. In this respect images are more precise and richer than literature. To say this is not to deny the expressive or imaginative quality of art, treating it as mere documentary evidence; the more imaginative the work, the more profoundly it allows us to share the artist's experience of the visible.[73]

Therefore, on the one hand, images, and photographs in particular, play a significant role in the documentation of a specific place and time, but it is also the medium and the creativity that realises the experience for an individual who bears witness. What is the purpose of this exchange? A crucial debate arises from this notion – who is responsible for the visibility of the image, the meanings derived, and the wider effect of these impressions – the artist or the witness? In a discussion on the role of oral testimony, historians Slim and Thompson write,

[73] Berger, John. *Ways of Seeing*. London: Penguin Books, 2008. 3. (First Edition 1972).

> The collection of testimony is not enough; to listen in order to bring about change means communicating what has been heard to those who can facilitate change […] Words can change lives, but only if people can be persuaded to listen and to act."[74]

Through Positive Eyes South Africa is one of many arts initiatives striving to bridge the individual therapeutic process with the public recognition of living testimony, not only by the spectator's encounter with the everyday, but also actively seeking out deeply engaged individuals and organisations who can and will facilitate change. This is why part of the process is to collaborate with local on-the-ground partner organisations; in South Africa, this was Positive Convention and its founder and director, Pholokgolo Ramothwala.[75] Through a shared creative experience, these individuals facilitate their own healing process; capturing photographs helps restore a sense of 'self' that disappeared with the diagnosis of an HIV-positive status. Individuals must feel ownership and the process of self-documentation contributes to this sense of empowerment as does the sense of belonging to a 'safe space'.

Significance of the 'Safe Space': Empowering the Human Spirit

As the drum circle began on our first day, individual sounds and movements joined to create an eclectic performance of rhythm under the guidance of South African musician, Steve Barnett. As the flow of the music travelled between us and within us, we sometimes connected and sometimes separated to create a discussion through movement on openness, containment and silence. At different moments, some people grabbed hands, some people turned away from the circle, some people came into the centre of the circle, some crisscrossed the circle to stand next to different people, some moved as individuals, some imitated others' movements, some focused on movement of the body while others focused on the beating of the drums. One woman even described the feeling "as if [she was] floating in the air" and so she needed to take off her shoes so

[74] Slim, M. and Thompson, P. *Listening for a Change: Oral Testimony and Development*. London: PANOS, 1993. 94.
[75] For more information on Positive Convention, see the website http://www.positiveconvention.co.za/.

she could "feel the ground beneath [her] with the soles of [her] feet."[76] We were asked to find a mantra to help us find our own space, and once we had that, we then had to link our spaces – as the beating of the drum came to a standstill, we ended where all we could hear was the syncopation of our breathing – in and out, in and out. This stirring experience was followed by a song and game initiated by two of the participants, Bongi and Nontya. Usually played by close friends, this in turn visibly relieved a lot of weight from the preconceptions and sensitivities inherently carried within each of us around HIV. The words to the song are as follows:

> Nganginesoka engangilithanda thanda kakhulu kunawo wonke
> (I had this boy friend that I loved more than the others)
> Lalithi malingibiza lithi sondela my love uthathu "hug", uthathu "mwa".
> (Whenever he calls me, he will say come closer my love and take your hug and take your kiss.)[77]

This chorus is repeated over and over as each individual chooses someone to bring into the circle and then that person chooses someone new to bring into the circle; no one leaves the circle without a hug and a kiss. From this moment on, twenty-six artists converted Arts on Main into their "safe space." But what defines a 'safe space'? Catherine Moon, an art therapist, describes the significance of creating a 'safe space' as an

> …atmosphere where each person is viewed as uniquely capable of artistic expression, where the process of creating is as important as what is created, where spontaneous expression and disciplined practice are understood to be interdependent aspects of creativity, and where both the person creating and the thing created are treated with respect and dignity.[78]

The space at Arts on Main was a forum to listen to each other, to see each other, to speak to each other, to hold each other and to experience empathy offered and returned throughout the ten-day intensive *Through Positive Eyes* process. The individual and the creation were treated with the utmost of 'respect and dignity' as the power of the process permeated us all. While it is imperative to realize that what feels safe and containing for one may have a completely different effect on

[76] Gugu. Music Session in *Through Positive Eyes South Africa*. UCLA Art|Global Health Center. 2 March 2010.
[77] Thank you to Bonginkosi, one of the *TPE* participants for translating this song for me. [December 2011]
[78] Moon, Catherine Hyland. *Studio Art Therapy: Cultivating the Artist Identity in the Art Therapist*. London: Jessica Kingsley Publishers, 2002. 71-72.

someone else;[79] ultimately the participants in *TPE South Africa* opened themselves up to contribute their own energy as individuals and as a group to create a welcoming 'safe space' to everyone.

This group dynamic was one of many in my own experiences but it was intriguing to see how interconnected the group became during such a short group process. Some research likens the early phase of group formation to an 'infant' who, still wholly dependent and adjusting to its 'mother' [or parent] experiences, is extremely sensitive to 'her' absence, generally creating considerable anxiety. It is only over time that the 'infant' personalizes and establishes a sense of being separate from its 'mother'.[80] In the same way, a therapy group can also experience this initial anxiety:

> Instead of a cohesive unit it is a fragmentary collection of individuals and what is aroused is anxiety rather than a pleasant merging.[81]

While this is not an in-depth analysis of the group dynamic, the general response of the *TPE* members was unlike that of a group "struggling to achieve a sense of being and unity."[82] The response resembled that of Gladys, one of the two non-South Africans, who spoke openly how in the light of the previous year's xenophobia in South Africa, she felt so "connected to everyone in the room" and she felt this would "become like another family for her."[83]

Art can achieve empowerment and develop agency in a way that few other channels of communication can because it opens up opportunities for the human spirit to express itself and its desires in a creative way. From a text entitled *Theatre and Empowerment*, empowerment is described as follows,

> Empowerment is to do not with the amelioration of oppression and poverty *per se*, but with the liberation of the human mind and spirit, and with the transformation of participants who

[79] Gray, A. *An Introduction to the Therapeutic Frame*. London: Routledge, 1994. 13.
[80] Nitsun, Morris. "Early Development: Linking the Individual and the Group." *Group Analysis*. Vol. 22. London: SAGE, 1989. 250.
[81] Nitsun, Morris. "Early Development: Linking the Individual and the Group." *Group Analysis*. Vol. 22. London: SAGE, 1989. 251.
[82] Nitsun, Morris. "Early Development: Linking the Individual and the Group." *Group Analysis*. Vol. 22. London: SAGE, 1989. 250.
[83] Gladys. Group Discussion in *Through Positive Eyes South Africa*. UCLA Art|Global Health Center. 2 March 2010.

> see themselves – and are often seen by others – as subhuman, operating only at the level of seeking merely to exist, into conscious beings aware of and claiming voices and choices in how their lives will be lived.[84]

Although this meaning is coming from an applied theatre perspective, this same notion of empowerment can certainly be applied to any artistic realm. This view focuses on the positive uplifting through liberation as opposed to the release from negative oppression; moreover, it is with this outlook that the *TPE* members achieved a cohesive group dynamic so early on in the process. The musical introduction of drumming, body movement and song opened the channels of creativity for the participants of *TPE* to create their own 'safe space' as they actively sought to challenge the status quo and empower themselves through artistic self-expression to reimagine and reveal a new image of HIV/AIDS in South Africa.

Taking a Stand: Art as a Tool of Resistance in South Africa

Although the focus of this thesis is on combating HIV/AIDS stigma in South Africa through art, it is essential to at least discuss briefly the history of art as a tool of resistance in South Africa as it is this history, which made it possible for an arts initiative like *Through Positive Eyes* to develop. With the impetus of the struggle years during the anti-apartheid movement, the arts in South Africa have been steeped in social and political activism. Sue Williamson, one of South Africa's most accomplished and internationally-known art critics, in addition to being an artist herself, is significantly responsible for the recognition of the impact of South African art as a tool of resistance and a vehicle for social and political transformation. In her Preface to the re-issue of her book *Resistance Art in South Africa*, she asks, "Is there an ethos that distinguishes South African art?," and she replies,

> It's hard to be definitive, but perhaps what was learned from growing up or being an artist during the struggle years was how to confront issues, whatever they might be, and how to use this in one's artistic practice. This desire to make work based on reality persists, and is coupled with an instinct to go for the jugular, not to hold back.[85]

[84] Boon, Richard and Plastow, Jane. "Introduction." *Theatre and Empowerment: Community Drama on the World Stage*. Eds. Richard Boon and Jane Plastow. Cambridge: Cambridge University Press, 2004. 7.
[85] Williamson, Sue. "Preface to the Re-issue." *Resistance Art in South Africa: Reissue of the Classic*. Cape Town: Double Storey Books, 2004. [Originally published in 1989].

In their determination to expose the reality of the fight against apartheid, artists like Paul Stopforth, Jane Alexander, Gavin Younge, William Kentridge, Ernest Cole, Sfiso Ka-Mkame, and Sam Nhlengethwa among others set the foundation of artistic resistance and lay the groundwork for artist activism to develop in South Africa.[86] They went "for the jugular" with their art, and they inspired the generation of artists after them to use art to revolutionize perceptions and stir activism. As Williamson writes in her recent book, *South African Art Now*,

> …the idea of the artist as carrying an unshakeable social responsibility, as being part of a larger community, and perhaps most important, of hitting hard and believing in the power of art to change attitudes, continues to affect the art production of this country [South Africa] to this day."[87]

Although the media and the themes differ, it is this groundwork that influenced artmakers to take action in the struggle against South Africa's 'new apartheid' – HIV/AIDS. While I mention both white and black South African 'resistance artists,' it is important to recognize that the reality of the time privileged the work of white artists significantly over the work of black artists. Although it would be ignorant to say that this has balanced out in the contemporary art world, Williamson does express her belief that "today contemporary South African artists – black and white – are enjoying a level of unprecedented access and visibility at home and abroad,"[88] but there are certainly still further efforts to be made for these artists to attain level support.

The *Make Art/Stop AIDS* initiative, under which *Through Positive Eyes* is one project, brought together international artists-activists including South Africans for a collaborative exhibition of HIV/AIDS-related works in "Not Alone."[89] Gideon Mendel along with other South African artists like Penny Siopis, Brenton Maart, Churchill Madikida, Zanele Muholi and David Goldblatt had pieces present in the show. Alongside the activists at the forefront like Zackie Achmat and the Treatment Action Campaign, these artists have all uniquely engaged, in their

[86] For further reading on this subject, see Sue Williamson's *Resistance Art in South Africa* (1989), Sue Williamson's *South African Art Now* (2009), William Cleveland's *Art and Upheaval* (2008).
[87] Williamson, Sue. *South African Art Now*. Collins Design, 2009. 46.
[88] Williamson, Sue. *South African Art Now*. Collins Design, 2009. 20.
[89] Catalogue for exhibition is available at http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf.

respective media, to challenge the prevailing images of the HIV/AIDS struggle – for treatment access, for acknowledgment, for workplace rights – and overwhelmingly against stigma. Images like Mendel's photo of the Treatment Action Campaign protest on World AIDS Day 2000 strikes a chord in the viewer because the intensity of both the resolve and the exhilaration of the activists is indisputable as they nearly charge through the image wearing their HIV-positive T-shirts:

Figure 15: *Treatment Action Campaign, Durban, South Africa*.[90]

As the arts gain respect and appreciation as a medium for counter-discourse, it is evident how "artmakers put forth personal, social, and political points of view, thus shaping national and cultural imaginary,"[91] to represent the reality around them for the benefit of observers in the present and in the future. The HIV-Positive T-Shirt initiated by the Treatment Action Campaign and its supporters was a trailblazing graphic artwork, which became a symbol of a new revolutionary style to lobby government for rights:

> Emblazoned 'HIV-Positive,' it has become far beyond South Africa's borders a symbol of the struggle for justice and reason and openness in the AIDS debate. […] It says we all bear this condition. We are all HIV POSITIVE.[92]

[90] Mendel, Gideon. *Treatment Action Campaign, Durban, South Africa – World AIDS Day 2000*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 195.
[91] Banks, Daniel. "Unperforming 'race': Strategies for Reimagining Identity." *A Boal Companion: Dialogues on Theatre and Cultural Politics*. Eds. Jan Cohen-Cruz and Mady Schutzman. New York and London: Routledge, 2006. 186.
[92] Cameron, Edwin. *Witness to AIDS*. Cape Town: Tafelberg Publishers Limited, 2005. 130.

The HIV-POSITIVE T-shirt is worn by both positive and negative individuals in a combined effort to transcend the barrier between stigamatiser and stigmatised as a strategy of unity in order to demand treatment with a greater voice.[93] Sociologist Erving Goffman, who wrote one of the foundational texts on stigma, writes about individuals "voluntarily [choosing] to wear a stigma symbol"[94] as a sign of disclosure. This t-shirt, like the well-known and well-worn red ribbon, became an iconic symbol for anyone who openly advocated and supported people living with HIV/AIDS; it contests stigma publically and proudly with love and encouragement. In her exploration of visual representations of the African body, cultural theorist and art historian Annwen Bates ascertains how the T-shirt has "become a metaphor for change towards greater personal awareness and community involvement" leading to an active, in contrast to the normally passive, representation of the 'African'.[95]

As the symbolism of the HIV-positive t-shirt spread with the intention to de-stigmatise, it is important to explore the significance of images in relation to stigma. It has been argued that what people accept to be true about themselves and about others is "incubated and articulated through the mediated images we ingest daily."[96] If this is the case, then when societies are confronted by images on a daily basis, fleetingly as many of them may be, the images can affect their perceptions of reality – their own and that of others. The relationship to images and the subsequent perceptions often vary based on the reality in which a person lives. This could therefore be considered a factor in the spread of stigma if a stigmatising image is etched into a society's gaze. Could not the same then be said for a de-stigmatising image? I would argue that in South Africa the use of mobile

[93] Also mentioned by Nathan Geffen in his *Debunking Delusions: The Inside Story of the Treatment Action Campaign*. Auckland Park, South Africa: Jacana Media, 2010. 28.
[94] Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963. 123.
[95] Bates, Annwen. "Wearing the T-shirt: an exploration of the ideological underpinnings of visual representations of the African body with HIV or AIDS." *African Journal of AIDS Research*. Vol. 6. No. 1. 2007. 72. [67-78.]
[96] Banks, Daniel. "Unperforming 'race': Strategies for Reimagining Identity." *A Boal Companion: Dialogues on Theatre and Cultural Politics*. Eds. Jan Cohen-Cruz and Mady Schutzman. New York and London: Routledge, 2006. 186.

media is crucial to the way information is communicated in urban and rural areas, and images are one aspect of this telecommunication.[97] One relevant example is when middle and high school students from government schools that spanned Gauteng, Limpopo, and Mpumalanga attended tours of the Make Art/Stop AIDS "Not Alone" exhibition. At least half of the students, if not more, captured photos on their cell phones of the various art pieces. Within seconds, these students were sending out messages en masse with photographs of themselves and Brasilian artist Adriana Bertini's "Condom Dresses," Indian artists Thukral and Tagra's underwear with its "Put It On" condom messages, and video clips shouting their message of choice into South African artist Langa Magwa's "Uphondo" (The Voice of the Affected and Infected).

Figure 16: *Uphondo (The Voice of the Affected and Infected)*[98]

But what of societies where these images are not part of the fabric or where people do not encounter these images? How then can stigma be gauged through an assessment of images? Different realities determine the visibility or invisibility of images. If representations of HIV/AIDS are

[97] In a study by Synovate, a Johannesburg-based market research company, it was determined that 82% of South Africans have a mobile phone, and of those 82% use their phones as cameras to take and send photographs. Evans, Sally. "SA can't live without cellphones." *Sunday Times Live*. 10 March 2010. [Online] Available: Http://www.timeslive.co.za/business/article348468.ece/SA-cant-live-without-cellphones [1 February 2012]

[98] Magwa, Langa. *Uphondo (The Vice of the Affected and Infected)*. 2007. UCLA Art|Global Health Center. Collection: Durban Art Gallery.

heavily laden with stigma but these images are not as readily seen in the public realities of certain societies, how can it be argued that images can be used to counter stigma? What triggers the same feelings of unworthiness and shame in the people who do not encounter the images of what Watney called thirty years ago, the 'Spectacle of AIDS'?'[99] I would argue that even if an actual image is not seen, the experience and sentiment that the image represents is experienced, thereby the same shame and worthlessness induced by the image is instead triggered by experience. Not everyone has the same exposure to images, if at all, or the exposure is through different channels of media, thereby changing the way in which the image is perceived. Internalised stigma in particular is unique to the reality of an individual's experiences, thereby creating internal imaging of oneself. This stigma is made even more difficult when social factors impinge on his humanity, thereby making him feel even more marginalised not just from HIV/AIDS stigma but from other mistreatments and prejudice. Paul Farmer argues,

> Social inequalities…are the motor force behind most human rights violation. In other words, violence against individuals is usually embedded in entrenched structural violence.[100]

It is these social inequalities from which stigma derives its strength as the nexus of all the historical, social, cultural, political, religious abuses; and the experiences of the corresponding degrading, shameful treatment produce an internalised sense of indignity. This socially constructed indignity and the decision to focus on surviving this indignity is vividly apparent in the narrative and images of *TPE* participant, Gugu Dlamini.

[99] Watney, Simon. "The Spectacle of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 46-59. [Essay originally published 1988.]
[100] Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor.* Berkeley: University of California Press, 2005. 219.

Figure 17: *Gugu's Self-Portrait*[101]

[101] Gugu. *Gugu's Self-Portrait*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

Power of Resilience: Living with the 'Rubbish'

During the initial workshop of *TPE South Africa*, Mendel, alongside fellow photographers Crispin Hughes[102] and Mikael Subotzky[103], first took the group through his own photographic journey of the pandemic in Africa. In quite an amazing twist of fate, one of his photos, taken in 2003, of 24 TAC activists who wanted to be part of a group portrait demanding access to ARV treatment included a familiar face to the *TPE* group – Gugu jumped up and shouted "That's me!"

Figure 18: *The Harsh Divide*.[104]

After nearly ten years, one of the women affiliated in this former project was one of the seventeen participants in the *Through Positive Eyes* initiative – 'once an activist, always an activist' Gugu declared proudly.

> Then I was helping those another women then who their children are HIV-positive then, and those people those women who are pregnant, who are waiting for the treatment the nevirapine to make their children then to be saved. Then I was fighting because I know the pain when a child go to through to that virus. There is many things in your head are you thinking. Then I was want to make sure then those children who are coming after our children, they are getting a better medication. There is a lot of stigma then. I think it will take time to make stigma to be finished. Before, we were fighting for treatment but now we were fighting for stigma almost of the time because it's quite a huge things. It's affecting all of us - our families, us and other people.[105]

From taking a stance against the government to demand treatment to taking a stance against society to combat stigma, Gugu is still here – her demand for treatment access got her ARVs; hopefully her

[102] For further information on photographer Crispin Hughes, see his website - http://www.crispinhughes.co.uk/. [1 February 2012].
[103] For more information on photographer Mikael Subotzky, see his website - http://www.subotzkystudio.com/. [1 February 2012].
[104] Mendel, Gideon. *The Harsh Divide.* 2003. Drama for Life. Web. Available: http://www.gideonmendel.com/. [1 February 2012]. NOTE: It was later realised that Gugu was not the only one in this original photo. Mlungisi Dlamini, another participant, was also present – 2nd from the left.
[105] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 1.

demand to stop stigma will find her peace. With single images like the one above, photographers – as visual artists – had to discern how to encapsulate the epidemic visually in order to engage with the public in a different way than some of the media's degrading and sensationalistic images. *TPE* sets out to do this by positioning the epidemic on a visual trajectory so that the participants and the observers can reflect on the use of a new language shifting the focus to the *living* epidemic away from its fatalized past.

Looking at Gugu's story, the transition thus far from the photo then *of her* to the photos now *by her* illustrates a change in her own self-esteem and a symbolic change through her on behalf of others who have followed a similar journey. Having looked through her 754 photographs, Gugu's work encompassed many aspects of her life including her home, being with her daughter, the local fruit and veg stall with friends, and her working as an activist. But as I engaged further in my own reading of Gugu's images, I found she had a siginificant repertoire of photos relating to rubbish scattered among her photographs – numerous images of rubbish, dumping grounds, and broken items. Gugu chooses to show through her own words and particularly her photographs that she lived with the rubbish and now she lives in spite of it. The metaphor of rubbish is a powerful point that would certainly stir emotions in someone who bears witness to Gugu's story. Once again it is apparent that while Sontag argues for the necessary eradication of metaphorical use in HIV/AIDS discussions,[106] it is through metaphor that Gugu understands and creates meaning in her images. As Treichler says so effectively and truthfully,

> No matter how much we may desire, with Susan Sontag, to resist treating illness as metaphor, illness *is* metaphor, and this semantic work – this effort to 'make sense of' AIDS – has to be done.[107]

While Sontag argues that metaphor and symbolism impact on the individual negatively, Treichler argues that nothing is free from social construction and therefore it is impossible for the theory of

[106] For further information, see Susan Sontag's *AIDS and Its Metaphors* (1990).
[107] Treichler, Paula. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge, Mass.: MIT Press, 1988. 34.

HIV/AIDS to be without signifiers, symbols and metaphors.[108] As I look more closely at Gugu's images, it becomes evident that she portrays herself and living with HIV through various metaphors – the first of which I will analyse is 'rubbish':

> I find out I'm HIV-positive because I've been raped. I'm a victim of rape. When I've been raped, they shoot me. They think I'm dead. Then when I in the hospital, I lay in the hospital three months in the coma.[109]

Reflective of Paul Farmer's discussion on "structural violence", Gugu's association with her 'rubbish' of rape, violence, trauma and an HIV-positive diagnosis explains why she absorbed such self-stigmatisation and shame. Even in today's South Africa, the legacy of apartheid is still present in daily interactions like the fact that majority of service venues have white customers and black staff, and the relationship between the two often still has an aura of superiority. It was only in 2008 that the University of the Free State experienced a scandal of white students who made a film, where treating black campus staff in the most degrading and humiliating manner was meant to be comic.[110] Through the expanse of the internet, copies of the film clip were seen around the world as South Africa once again came into the limelight for its persistent racial challenges. So for those who may not encounter visual images, stigma can also be built from this experiential imaging. As a South African black, HIV-positive female, Gugu has demonstrably internalised the remnants of the apartheid system – poverty, abuse, sense of inferiority, sexual violence – and the significance of why she equates herself to rubbish is seen in both her descriptions and my interpretations of her images.

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[108] Treichler, Paula. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge, Mass.: MIT Press, 1988. 34-35.

[109] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 1.

[110] Msomi, Sinothile and Shilaho, Westen. "Racism Still a Threat to South Africa." *The Centre for the Study of Violence and Reconciliation*. c2008. Web. Available: http://www.csvr.org.za/index.php?option=com_content&view=article&id=2262:racism-still-a-threat-to-south-africas-democracy&catid=139:media-articles&Itemid=37. [1 February 2012].

Figure 19: *Pile of Stones*.[111]

Figure 20: *Broken Cacti.*[112]

In the first two images, we see pieces of stone with shards of broken glass in one corner and plastic bottles strewn about, and in the other, the pile of rotting, broken cacti piled on a dumpster. Based on Gugu's interview and my own interpretation of these images, Gugu herself felt like she was an outcast like the rubbish rotting away after she learned of her diagnosis. Although she expresses the support she received from her mother and later a support group, she also describes repeated experiences with stigma because of her status which made her feel very depressed and believe she was going to die.[113]

Figure 21: *Plastic Bottle Collector.*[114]

Figure 22: *Glasses.*[115]

In the second two images, what we see at first glance is not necessarily what is being shown. On the one hand, we see an image of a man wheeling his load that from afar looks like rubbish – but at

[111] Gugu, Photographer. "Untitled." March 2010. From UCLA Art|Global Health Center.
[112] Gugu. *Broken Cacti*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.
[113] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 1.
[114] Gugu. *Plastic Bottle Collector*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.
[115] Gugu. *Glasses*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

a closer look, it seems to be the rubbish of others, but for him it is plastic bottles that he has collected to make a living for himself. These bottle-collectors travel around from home to home digging through the rubbish bins standing outside the high walls and electric fences of homes they will likely never acquire. What does it say when a person's living comes from sorting through the trash of others? It is certainly a commentary on the perpetual fragmentation between the 'Self' and the 'Other' within class divisions, and this is what Gugu's image expresses. She herself has had to collect the rubbish thrown her way and sort through it with her own coping mechanisms, and *TPE* provided a new way to express her internalised emotions. As I explained earlier, the blatant social inequalities and class divisions still present in South Africa lend to even further marginalisation when HIV/AIDS enters the frame. Writing about this 'overlap,' Paul Farmer asserts,

> The distribution of AIDS is strikingly localized and nonrandom; so is that of human rights abuses. Both HIV transmission and human rights abuses are social processes and are embedded, most often, in the inegalitarian social structures I have called structural violence. […] There is considerable overlap between 'groups at risk': if you are likely to be tortured or otherwise abused, you are also likely to be in the AIDS risk group composed of the poor and the defenseless.[116]

Gugu's image of the two glasses could also be interpreted as a distinction between what is whole and what is broken, for she has taken the photo not just of one or the other but of both glasses. But having met Gugu and the way she speaks about her life, I would say through this image it is important to see that things can break, but it is also essential to see what has not broken. In this way she speaks so positively about her relationship with her daughter – a child born of rape - who Gugu sees as her main reason to live:

> Don't be scared for anyone. Just make sure you live your life. Be proud. I will become stronger. I'm not a dying type. I will wait until you reach you finish your school, then you finish your university. Then I know there is the day I suppose then to go and die. Then just we will wait until that day. But I'm telling you, I ask God and I pray to God to say 'Please, God, can you give that power and strength to make my child to grow before you call me.'[117]

[116] Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berkeley: University of California Press, 2005. 219.
[117] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 3.

It is continuously evident that the strength Gugu retains for her will to live is heavily supported by her continual emphasis on what she has, rather than what she does not have. While generally the disintegration of self-esteem is inherent with diagnoses of any illness, it is even moreso with HIV because of the intense stigma surrounding it. As pointed out by CAPRISA[118] community AIDS activist and community health researcher Janet Frolich,

> Fear of stigma can produce extreme anxiety about sharing one's HIV status with others… People who do share their HIV or AIDS diagnosis with family or friends lay themselves open to stigmatisation, isolation, and potential loss of self-esteem. […] Yet keeping the diagnosis of HIV a secret is very likely to hinder a person's ability to develop effective coping strategies, leaving them all the more vulnerable to fear, anger and depression.[119]

So while isolation may lead to further suppression of feelings post-disclosure, a person can also be overwhelmed by the fear of stigmatisation. Thus, there is no 'right' decision and ultimately, it is up to the individual to decide when he is ready to disclose, if ever. Gugu aims to be a reflection of HIV-positive individuals living in South Africa by openly discussing her challenges with self-induced and socially-induced stigma, but she does not deny her feelings of guilt and anger either. After learning of her diagnosis and needing to escape the stigma of her family, Gugu speaks of her independent decision for disclosure following a disturbing incident when she was stigmatised by a pastor:

> I left home. I go to stay in the center. […] when I arrive in the center, that pastor - he brought me in the center - he advised me then not disclose my status. But it was actually hard to me. I was supposed because I was seems I'm living with the hard stone inside my heart. […] I end up disclosing my status…then he started then to discriminate me. 'Don't touch some of the baby in the center, because they will get your virus. Don't cook for children.' I can't stay here then because I will end up having anger, I will end up didn't accept myself. Then I end up left the center. […] If I didn't disclose my status, I was feeling then there was something inside to my heart. I was feeling guilt. That's why I decide then to disclose my status That's why I'm living a healthy life, I'm living. […]I want to tell those people who are HIV-positive then to be openly, and to make sure they live their life. Don't care about anybody else. Just live your positive life. You will become stronger and stronger and stronger again. [120]

[118] For more information on the Centre for the AIDS Programme of Research in South Africa (CAPSA), see the website http://www.caprisa.org/SitePages/Home.aspx. [1 February 2012].
[119] Frolich, Janet. "The impact of AIDS on the community." Karim. S. S., Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008. 355.
[120] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 2.

In the following series, Gugu makes a powerful statement through her images of climbing out of a rubbish bin. First, one must ask what does it mean to put oneself inside a rubbish bin physically and to feel like this is where one belonged at some point in his life story? Of course, there will be different interpretations by witnesses to this series, but I will elaborate on my own interpretations based on my own experiences with Gugu. As she journeys through the healing process, the coming out of the rubbish bin could relate to her becoming "stronger and stronger and stronger" as she strives to let go of the stigmatising experiences she confronted throughout her traumatic life. Archbishop Desmond Tutu's description in his forward to Sue Williamson's text on South African resistance art in the apartheid era is relevant to describing this type of transcendence:

> …it's important that people know that in being creative they become more than just consumers. They can transcend their often horrendous circumstances and bring something new into being.[121]

It is alarming that Gugu's images show that she considered herself not only like the rubbish in the bin, but that this is where she once felt she belonged – a total outcast. But during the *TPE* group discussions, the way she spoke about her will to live and the way her photos demonstrate this, she effectively described her own transcendent experience through artistic expression in the *TPE* process. Especially when Mendel's "Harsh Divide" image appeared, Gugu emphasized how amazing it was to still be alive ten years later, for she decided to accept herself and her status without someone else infringing on her own self-value like the pastor, like her rapist, like anyone who stigmatised her. Certainly, it is not completely possible to erase the discrimination and pain, 'the rubbish,' that others inflicted upon her, but she empowers herself with these images by showing that she has the choice in how she lets the 'rubbish' of her life impact on her living today. As Gugu captures her physical body coming out of a rubbish bin, the images inherently carry the undertone of a personal breakthrough in stigmatisation.

[121] Tutu, Archbishop Desmond. "Foreword." Williamson, Sue. *Resistance Art in South Africa: Reissue of the Classic*. Cape Town: Double Storey Books, 2004. [Originally published in 1989].

Figure: 23: *Rubbish Series*.[122]

Gugu is one of the few participants who arranged to capture a moving series of action photographs with her digital camera. From being completely hidden in the rubbish bin, the observer witnesses a very slow emergence until the last few photos where Gugu stretches and dances happily away from the row of bins. This might appear to some as quite contrived, but Gugu describes this series in

[122] Gugu. *Rubbish Series*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

relation to the slow process and difficulty of disclosure for her, yet once she was open about her status, she was filled with relief and attained a higher level of acceptance to live with HIV:

> Then to say like me then to that bin, it's hard sometimes to come out. But you suppose then to have that strength and power to coming out. After that you live your life without stress, peacefully.[123]

While it would be naïve to claim that Gugu's sense of self-love was fully accomplished in a project like this one, it is apparent in Gugu's journey as well as the others that *TPE* certainly fosters a space for individuals to experience new breakthroughs of their own barriers in a process of de-stigmatising themselves and their identities. By undergoing the process of recollection and visually depicting phases of one's life, drawing on where one has been, where one is now, and where one wants to be, the sharing of one's life story, even fragments, is a way of confirming one's existence; this is the poignancy of the experience.

What is also telling is that even though *TPE* is an individual process, the collective group also plays a role in the overall journey of de-stigmatisation and self-love. In the same way the motivation behind the concept of "Cultural Citizenship" is described as "to create a space where people feel 'safe' and 'at home,' where they feel a sense of belonging,"[124] it is only once the collective has conclusively agreed to the feel of the space that the process of healing can really begin. In an initial group discussion, the inner conflict between self-hate and self-love contributed to the effect of the overall healing process for the group. Having now seen Gugu's 'Rubbish' series, it is imperative to also see the symbolic 'Water' series she shares of her search for her own self-acceptance. Water archetypically and religiously symbolizes feelings of purification, growth, and renewal. What does Gugu's trajectory demonstrate from her "Rubbish Series" to this "Water series"?

[123] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 4.
[124] Flores, William V. and Rita Benmayor. "Introduction: Constructing Cultural Citizenship." *Latino Cultural Citizenship*. Flores, William V, and Benmayor, Rita. Eds. Boston: Beacon Press, 1998. 15.

Figure 24: *Water Series*[125]

In looking at the images on a literal level, it would seem that Gugu wants to depict cleansing herself from the rubbish in her life. But it is essential to look deeper into this contrast – why is it that Gugu chooses to portray this purification process in her images? Is there a need to show other people that she is now clean? This is significant to her past as a victim of rape, where often women feel the need to repeatedly clean themselves in order to feel whole again, a common symptom of post-traumatic stress disorder associated with rape. In this vein, Gugu can represent women who have experienced this same emotive intensity for South Africa has one of the highest rates of rape and sexual assault.[126] And yet even as part of the on-going healing process, this feeling of being clean again is very difficult to achieve. Another interpretation could be that she is cleansing herself of the stigma attached to HIV. In her exploration of manufactured images of Africa, Ruth Mayer looks more closely at the metaphor "Africa is a Virus," and she describes 'the virus' as having a

[125] Gugu. *Water Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[126] "Background Note: South Africa." *U.S. Department of State, Bureau of African Affairs*. 30 January 2012. Web. Available: http://www.state.gov/r/pa/ei/bgn/2898.htm. [1 February 2012]

> …special affinity to the imagery of Africanity. No other continent has ever gained as dangerous connotation as the African, and the virus seems to slip easily into the place of older, colonial fears and projections…[127]

Not only does HIV encompass this rubbish of the past, but because of its laden sexual connotations, often the HIV-positive individual is also associated with dirtiness, contamination, and impurity, and therefore the water is her resource for purification not just of her body but of her soul. This can be a quite intense interpretation in connection with the widespread religious belief that HIV is a punishment from God.[128] Ultimately, it is in representation that the link of HIV/AIDS with 'promiscuity, ''immorality' and 'punishment' continues to infiltrate deeper and deeper into the discourse of HIV and AIDS, thus spawning a persuasive internal and external stigma to burden those living with the infection. Certainly, Gugu's was part of the decision to create these images as part of her self-portrait, but she also straightforwardly describes her own interpretation of why she photographed this "Water Series":

> I want then to make people then to understand to say, sometimes when you have started to diagnose my stat– your status, then you feel like you're drowning in the water. You feel like there is no-one who gonna save you. But when you understand yourself. You will become saved. When you accept your status, it's become quite clear and you will accept yourself.[129]

While Gugu describes the water as a drowning force to be reckoned with, she explains that once she accepted her status and found purpose in her life, she was able to save herself from the water. As water can symbolize both birth and death, it became a source of renewal for living with HIV, a renewal in spite of the rubbish, which Gugu later describes in her desire for people to see her pain but also her happiness. These images are not meant to reflect a binary of 'good' or 'bad' images reflecting HIV/AIDS, or as Kylie Thomas attests, the need to do more than "replacing a 'negative' image with a 'positive' one"[130]; the *TPE* images fall on both sides of the representational spectrum

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[127] Mayer, Ruth. "Don't Touch! Africa is a Virus!" *Artificial Africas: Colonial Images*. Dartmouth: University Press of New England, 2002. 257-258.
[128] Peters, Reverend A. Stephen. "HIV/AIDS: Is It God's Judgment?: A Christian View of Faith, Hope and Love." *The Body: The Complete HIV/AIDS Resource*. 1994. Web. Available: Http://www.thebody.com/content/art5908.html. [1 February 2012]
[129] Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 4.
[130] Thomas, Kylie. "Selling Sorrow: testimony, representation and images of HIV-positive South African women." *Social Dynamics* 34.2 (September 2008): 220.

– and this is crucial to effectively combating stigma. One can not ignore the fact that people *are still dying* from AIDS complications in South Africa because they may still not have access to treatment, and these individuals must still be represented but this must not be the only representation – the reality of living with HIV must also be portrayed – and in the *TPE* model, it is. Gugu follows in the footsteps of her predecessor South African artists when she "goes for the jugular" as Sue Williamson calls it, to extend herself beyond her boundaries to achieve the message she wants to communicate through her narrative and photographs.

The burden of representation has particularly affected images of people living with HIV/AIDS in Africa, where the highly contested but widely utilized term, 'African AIDS,' has been applied almost as if citizens of African countries have an even dirtier, more contagious strain of the virus. Just as 'Africa' became the epitome of everything that is not Western, 'African AIDS' compelled by Western manipulation of knowledge, became the 'Other' within the 'Other'. Treichler elaborates on how this manipulated knowledge hinges on the legacy of dichotomies, relegated by the West, on which "the discourse of AIDS attaches itself [and] reinvigorates them [the dichotomies]…"[131] The irony of this 'Western' intention is that the reach of HIV/AIDS is so vast and complex that AIDS narratives interweave and unravel across these boundaries of difference, especially in the African context. The question then and now remains – can a photograph candidly depict a person *living with* HIV/AIDS when the universal visual vocabulary is besieged by images of disgrace, and if it is possible, can the photograph truly portray the substantial complexities of living with HIV/AIDS? The essence of *Through Positive Eyes* is not to portray the 'perfect life' or claiming to portray the 'complete life' but that it encourages portrayal of the reality of living with HIV including the challenges of the past and present. As I engaged with Gugu's images from the *Through Positive Eyes* process, in the section that follows, I will engage with the burden of representation that has been linked to images of people living with HIV/AIDS over the past three decades.

[131] Treichler, Paula A. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press, 1999. 7.

The Burden of Social Construction: Visual Vocabulary of HIV/AIDS

> AIDS does not exist apart from the practices that conceptualize it, represent it, and respond to it. We know AIDS only in and through those practices. This assertion does not contest the existence of viruses, antibodies, infections, or transmission routes. Least of all does it contest the reality of illness, suffering, and death. What it *does* contest is the notion that there is an underlying reality of AIDS, upon which are constructed the representations, or the culture, or the politics of AIDS. If we recognize that AIDS exists only in and through these constructions, then hopefully we can also recognize the imperative to know them, analyze them, and wrest control of them.[132]
>
> - Douglas Crimp

> We cannot accept the dominant image of people with HIV as totally isolated, pathetic, silent, hospitalized, dying 'AIDS victims'. We have to transform the terms in which AIDS is *thought* (and feared, and dreaded, and made the stuff of countless nightmares, or entirely disavowed), in order to improve the circumstances in which people with HIV live. This means taking liberties in every sense of those words.[133]
>
> - Simon Watney

In order to understand the paradigm in which people living with HIV/AIDS have been represented, it is essential to trace the trajectory of these images in photography. The camera comprises its own visual lexicon – and it us up to the photographer to decide which expression will capture what he wants to portray. The challenge for the radical photographer who wants to shift this paradigm is how to tackle the connotations conferred onto the visual lexicon by pre-existing structures and social conditions. In her critical analysis of moral and aesthetic issues in photography, cultural theorist and political activist Susan Sontag expands on the notion of a new visual code:

> In teaching us a new visual code, photographs alter and enlarge our notions of what is worth looking at and what we have a right to observe. They are a grammar and, even more importantly, an ethics of seeing.[134]

Particularly due to the mass production and dissemination of images, this new 'ethics of seeing' encompasses the semiotic vocabulary with which one is familiar from previously observed images, but it also lends itself to the potential misappropriation of reality with photographic subjectivity.

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[132] Crimp, Douglas. "AIDS: Cultural Analysis/Cultural Activism." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge, Mass.: MIT Press, 1988. 3.
[133] Watney, Simon. "An Introduction." *Taking Liberties: AIDS and Cultural Politics*. Eds. Erica Carter and Simon Watney. London: Serpents Tail, 1989. 49.
[134] Sontag, Susan. *On Photography*. London: Penguin Books, 2008. 3. [Originally published in 1977].

Any dialogue on HIV and AIDS inherently comprises a whole array of loaded perceptions and misperceptions, notions and misnomers, myths and truths, and most images pertaining to HIV and AIDS are infiltrated with the same as part of a pre-established visual lexicon. Edwin Cameron writes, "AIDS is an epidemic enmeshed with sex and death. In Africa the epidemic is enmeshed with politics of race and sex and death."[135] Society has been so overburdened with the correlation between HIV/AIDS and sex because of its transmission, and death because of its link to hopelessness, that to rectify this burden of representation, a shift in the paradigmatic imaginary of HIV/AIDS is necessarily inevitable. When the 'politics of race' enters the picture, the stigma attached to HIV/AIDS grows twofold. Sex, death and race comprised the photographic medium – the merchant of images to the world of what HIV and AIDS looked like:

Figure 25: *Homosexual AIDS Patient.*[136]

Figure 26: *African AIDS Patient.*[137]

These two images are placed intentionally out of context side by side – one of a homosexual man suffering of AIDS complications and one of an 'African' man suffering from AIDS complications. Although I draw on theorists who wrote on HIV/AIDS in the early years of the epidemic and make claims based on the context in which they lived then, I accessed these two images in 2011 when I

[135] Cameron, Edwin. *Witness to AIDS*. Cape Town: Tafelberg Publishers Limited, 2005. 75.
[136] Reininger, Alon. *Homosexual AIDS Patient.* 31 May 2011. Contact Press Images. Web. Available: http://www.nytimes.com/2011/05/31/health/31aids.html?pagewanted=all. [1 February 2012].
[137] Artist Unknown. *African AIDS Patient*. n.d. Web. Available: http://scrapetv.com/News/News%20Pages/Health/Pages/AIDS-loses-lustre-after-being-exposed-as-a-bully-Scrape-TV-The-World-on-your-side.html. [1 February 2012].

entered 'AIDS and Images' into a Google search. Even thirty years later, the representation and visual vocabulary of HIV/AIDS is still significantly problematic, thus supporting my argument. Even after going to the websites from which Google extracted the images, the 'African' remained 'just another [nameless] African' dying from AIDS haphazardly placed as the 'dying photo' in a 2008 article. And even though the image of the 'homosexual man' contained a bit more information on the human in the photo, the use of his name was merely due process for this 1986 image, which opened a 2011 *New York Times* article on the three decades since the discovery of AIDS. Both photographs are prime examples of the way in which the media exploits individuals and manipulates images, conducting the channels through which society engages with images of people *living with*, or rather *dying from*, AIDS. The linguistic and visual metaphors used to describe HIV and AIDS have continued in spite of Susan Sontag's definitive text, *AIDS and Its Metaphors*, where she argues for the necessity to end the metaphorical 'battlefield' and engage directly with the epidemic itself and what it signifies for the person living with the virus:

> …the effect of the military imagery on thinking about sickness and health is far from inconsequential. It overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and stigmatizing of the ill…We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy. We – medicine, society – are not authorized to fight back by any means whatever…[138]

But as I expressed previously, often it is through metaphors that we gain our perceptions and understanding of certain ideas, and while Sontag's argument is ideal theoretically, practically it is impossible. HIV and AIDS have assumed many different representations – all of which are heavily mediated by factors of race, sexuality, and class. Sontag contends that because "AIDS seems to foster ominous fantasies about a disease that is a marker of both individual and social vulnerabilities,"[139] the 'vulnerable,' or 'marginal,' or 'subaltern,' populations become the 'plague'

[138] Sontag, Susan. *AIDS and Its Metaphors*. London: Penguin Books, 1990. 95. [First published 1989].
[139] Sontag, Susan. *AIDS and Its Metaphors*. London: Penguin Books, 1990. 66. [First published 1989.]

of society; and, 'plague' is "the principal metaphor by which the AIDS epidemic is understood."[140] Plague and illness are often associated with these populations to give the elite something, or someone, to disdain and although HIV itself does not recognize or care who it infects, its impact particularly in the populations of lower socio-economic status, continues to be part of the critical discussions today around poverty and access to medical care. Medical doctor and anthropologist, Paul Farmer, is one of the leading activists in the medical profession championing the rights of the impoverished globally. Having written on the blame-game of the Haitian scapegoat of HIV transmission to the West, he expands on the inferiority of the Haitian medical structure as a global ethical problem also reflected in the rest of the world's poor populations:

> Surely it is an ethical problem that in the coming year an estimated six million people will die of tuberculosis, malaria, and AIDS – three treatable diseases that reap their grim harvest almost exclusively among populations without access to modern medical care. These deaths are reflections of structural violence and should be a central concern for the human rights community.[141]

Farmer's concern for the need to develop a human rights paradigm to confront the antagonism of 'structural violence' is paralleled by the need for a new paradigm in the HIV/AIDS imaginary. In the past, this sort of dialogue and thought was not even a glimmer in the media's rhythmic portrayal of individuals covered in blistering lesions, jaws jutting out from sunken cheek bones with no recourse but to waste away with no one but medical practitioners in masks afraid to catch the deadly virus –

> The 'other' subject of AIDS is the person with AIDS, bound, gagged, and hidden away behind the antiseptic screens and curtains of AIDS commentary, which are occasionally pulled to one side in order to reveal the elaborately stage-managed spectacle of the monstrous.[142]

Immediately after reading Watney's quote, this piece by South African artist Penny Siopis came to mind as a prime example of the changing visual lexicon of HIV/AIDS.

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[140] Sontag, Susan. *AIDS and Its Metaphors*. London: Penguin Books, 1990. 44. [First published 1989.]
[141] Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berkeley: University of California Press, 2005. 22.
[142] Watney, Simon. "The Subject of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 28. [Essay first published 1987.]

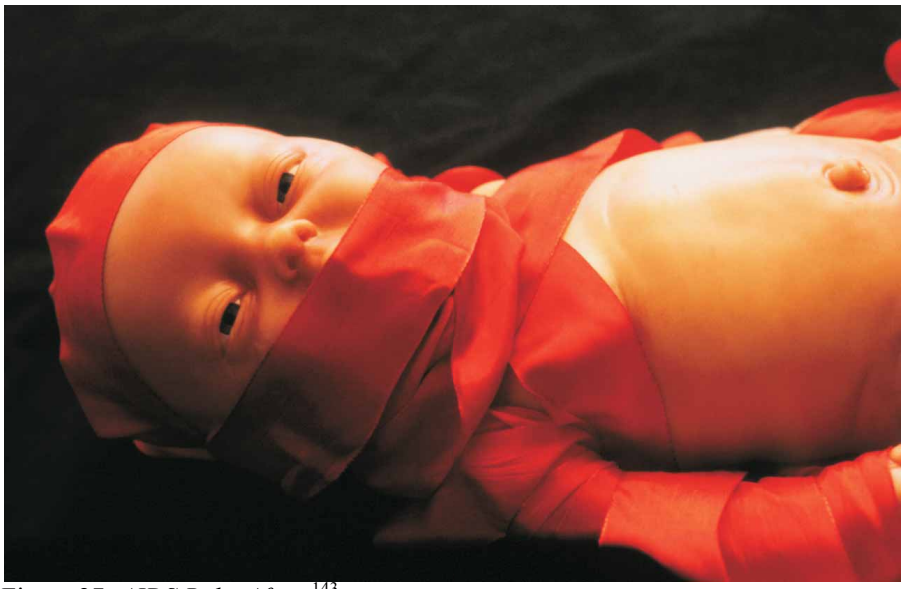


Figure 27: *AIDS Baby Africa*[143]

Although Siopis' intention was to utilize the red ribbon in a way so that it "became less symbol, motif, logo than a representation of flesh and blood,"[144] many meanings have been deduced from this image as I learned while assisting with educational tours of the exhibition including this image. From the inability of the baby born with HIV to speak up for its own access to ARV treatment to the suffocation of society by the excessive use of the red ribbon to the red ribbon symbolizing the mother's umbilical cord – with any meaning, this piece disturbs its viewer for good reason as does Watney's image of the 'bound, gagged and hidden away 'other' subject of AIDS'. With such a "bleak and complex backdrop of AIDS (dis)information," images in the media "obscure the reality that many PLWAs continue to lead full, 'normal lives',"[145] signifying the need for an impetus of transformation. As Cindy Patton sets this scene for her readers to understand how AIDS became a denigrating social construction invented by the West, so Simon Watney clarifies why images of people *living with* HIV or AIDS was too risky for the Western social and political agenda. The implication of an image of a PLWA leading a 'normal life' would be that there is no 'one look' of HIV/AIDS and 'remorsefully' maybe even foster compassion. The desired intention is that society

[143] Siopis, Penny. *AIDS Baby Africa*. 1996. *Not Alone* Catalogue. UCLA Art|Global Health Center.
[144] Siopis, Penny. *Not Alone Catalogue.* Web. Available: http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf. [1 February 2012].
[145] Patton, Cindy. *Inventing AIDS.* New York and London: Routledge, 1990. 27.

knows exactly what AIDS 'looks like', that "any possibility of positive sympathetic identification with actual people with AIDS is entirely expunged from the field of vision,"[146] and that any image would immediately associate with one of the 'at-risk groups', or as Watney prefers, 'highly vulnerable groups'[147] e.g. homosexual, African, black, IDU, sex workers, etc – and it is these groups that make up the 'Other' of the HIV/AIDS paradigm. In the argument he makes in *Orientalism,* cultural theorist Edward Said describes the 'us' and 'them' dichotomy as a "political vision of reality whose structure promoted the difference between the familiar (Europe, the West, 'us') and the strange (the Orient, the East, 'them')," a distinction which was quickly appropriated to various facets of social constructions with the advantage always on the side of the West because "he was the stronger culture, he could penetrate, he could wrestle with, he could give shape and meaning to the great Asiatic [or African] mystery…"[148] This Western essentialism of the 'Other' onto the HIV/AIDS platform severely quarantined many individuals who were already among the 'persecuted', further thrusting HIV/AIDS into desolate images of the macabre. This immediate association of AIDS with death in images is further complicated by the different faces of death that emerge:

> What we are typically shown is a face we already know and recognize from AIDS commentary – the face of death, staring out at us with an expression of unbearable intensity and complexity. Whatever such people might be thinking, is silenced by the full weight of an agenda which constructs them unambiguously as morbid and above all *admonitory* signs of the deadly danger of sex outside the confines of the family. The unconscious of such photography is brutally direct: Homosexuality = AIDS = Death.[149]

Watney distinguishes the faces of death from the physical face of death to the subtle allusion of impending death awaiting those who belong to a 'vulnerable group'. Even in his concluding

[146] Watney, Simon. "The Spectacle of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 52. [Essay first published 1988.]
[147] Watney, Simon. "The Subject of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 25. [Essay first published 1987.]
[148] Said, Edward. *Orientalism*. New York: Vintage Books, 1979. 43-44.
[149] Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 66. [Essay first published 1988.]

equation 'Homosexuality = AIDS = Death, in reference to its predecessor SILENCE = DEATH, any 'vulnerable group' can precede the AIDS = DEATH equation.[150]

Figure 28: *Silence = Death.*[151]

While Watney alludes to 'death,' implied in the content of the images, there is a dual meaning around the notion that a photograph itself can be understood to symbolize mortality. Sontag describes, "All photographs are *memento mori*. To take a photograph is to participate in another person's mortality, vulnerability, mutability."[152] Inevitably, artists and activists alike, ultimately needed to contribute actively to transform the paradigm of *dying from* AIDS to a paradigm incorporating all the complexities of *living with* HIV/AIDS.[153] Photography plays a key role in this transformational process: on the one hand, it is evident how images can change a person living with AIDS into the symbolic 'AIDS victim,' but on the other hand, Watney emphasizes how "they themselves [people living with HIV/AIDS] are actively contesting and resisting the discursive structures which they have been made to embody."[154]

[150] Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 66. [Essay first published 1988.]
[151] Elo. Weblog entry. *Great Political Posters That Changed U.S. History.* Think Smart Designs Blog. Available: http://thinksmartdesigns.blogspot.com/2010/06/great-political-posters-that-changed-us.html., June 2010. Web. [1 February 2012].
[152] Sontag, Susan. *On Photography*. London: Penguin Books, 2008. 10. [Originally published in 1977].
[153] This notion is discussed in Griffin, Gabriele. "Introduction." *Representations of HIV/AIDS: visibility blue/s*. Manchester: Manchester University Press, 2000. 8. AND in Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 69. [Essay originally published in 1988.]
[154] Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 67. [Essay originally published in 1988.]

From colonialism to the present-day, Western projections further proliferate the unrelenting dehumanization of Africa and Africans as a necessary foil to the West in order to put their imprudent angst and anxiety at ease for "the West seems to suffer deep anxieties about the precariousness of its civilization and [has] a need for constant reassurance by comparison with Africa."[155] As the West continues to represent 'Africa' through the lens of its prejudices, AIDS or otherwise, Achebe writes, Conrad's "'heart of darkness' plagues us still."[156] – "It was and is the dominant image of Africa in the Western imagination."[157] Therefore, I argue that a transformation is not only essential for the images signifying HIV/AIDS in general, but also around the image of HIV/AIDS in Africa. As my analysis in the next chapter shows, *Through Positive Eyes* fosters a space for the 17 participants to engage with their creative intuitions and 'resist' the dominant photographic paradigm that has continued to feed the persistence of stigma. By re-inventing their own contemporary reflections of HIV/AIDS in South Africa, I explore three self-portraits through which the adverse representations of Africa are negated as they breathe 'resilience' into their images and de-stigmatise themselves to redefine today's reality of HIV/AIDS in South Africa with all its complexities.

[155] Achebe, Chinua. "An Image of Africa: Racism in Conrad's *Heart of Darkness*." In *W. W. Norton & Company's Critical Edition of Joseph Conrad's Heart of Darkness*. 1988. 261.
[156] Achebe, Chinua. "An Image of Africa: Racism in Conrad's *Heart of Darkness*." In W. W. Norton & Company's Critical Edition of Joseph Conrad's Heart of Darkness. 1988. 259.
[157] Achebe, Chinua. "An Image of Africa: Racism in Conrad's *Heart of Darkness*." In W. W. Norton & Company's Critical Edition of Joseph Conrad's Heart of Darkness. 1988. 261.

CHAPTER TWO:
DESTIGMATIZATION: FROM SHAME TO ACCEPTANCE

> Stigma – the situation of the individual who is disqualified from full social acceptance.[158]
>
> - Erving Goffman

> Even myself, I could not accept myself, as a person who's living with AIDS.[159]
>
> - Pleasure

> HIV is not the world with no exits. I took it as a situation that one needs to have so that you could transform…that is why I try at all costs to live positively…Really I am going to succeed in fighting HIV and AIDS.[160]
>
> - Ludick

Stigma exists at the beginning of one's journey with the first diagnosis of an HIV-positive status and carries on as a challenge throughout the process of secrecy and shame, disclosure, and hopefully, ultimately acceptance. As I argued in the first chapter, stigma does not just supernaturally appear; it is a product of the globally imposed prejudices Paul Farmer, among others, strategically term "structural violence." Similar to the notion of "global apartheid,"[161] "structural violence" is a term that connotes a range of human rights abuses including

> …extreme and relative poverty, social inequalities ranging from racism to gender inequality, and the more spectacular forms of violence that are uncontestedly human rights abuses, some of them punishment for efforts to escape structural violence…"[162]

When the mechanisms of power institute a sense of superiority over people in an already impoverished state, and then act on this power with violence, the inequalities of marginalised people are further exacerbated. This signified inferiority is a crucial factor in enabling the persistence of stigma in the social milieu of a people. While social injustice exists in many forms in South Africa, stigma of people living with HIV/AIDS has permeated its public and private environs. In this second chapter, I look more closely at images from three participants to demonstrate that

[158] Goffman, Erving. "Preface." *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963. 9.
[159] Pleasure. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 1.
[160] , Ludick. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 11 March 2010. 5.
[161] Booker, Salih and Minter, William. "Global Apartheid." *The Nation*. 21 June 2001. Web. Available: http://www.thenation.com/print/article/global-apartheid. [1 February 2012].
[162] Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berkeley: University of California Press, 2005. 8.

TPE is a model for how photography can be used as a tool of de-stigmatisation that can be employed by HIV-positive individuals to accept their status. The transformation of the evolving HIV/AIDS paradigm, steering from the emphasis on *dying from* AIDS complications and embracing the self-portraits of *living with* HIV/AIDS, contributes to the process of de-stigmatisation.

Impact of Social Stigma on Internalised Stigma

Erving Goffman contends that stigma is "of course derived from society, for ordinarily before a difference can matter much it must be conceptualized collectively by the society as a whole"[163]; therefore, it is only once society highlights the disparity, that it can then be stigmatised. While social stigma has its own complexities and demoralizing effect on HIV-positive individuals, it also generates an internalised stigma that one carries, which can be just as crushing if not more than social stigma as it is a uniquely private burden. As I wrote previously, the public and private stigma are necessarily bound but the private stigma sits deep within a person, often pushing the infected individual into a withdrawn internal world of depression and isolation. In their analysis of the 'social risks' for HIV-positive individuals, medical sociologist Gill Green and medical anthropologist Elisa Sobo attest to the intense self-loathing that can consume a stigmatised individual:

> Self-hatred and shame develop from internalising a negative valuation of one's self or body. The discrepancy between what is expected in a 'normal' individual and what is actual in a stigmatised individual spoils the social identity [of that person]…[164]

The HIV-positive person ends up often feeling caught between these two realities of what they have learned is 'normal' and what they are perceived to be as the stigmatised individual.

Although all seventeen *TPE South Africa* narratives include experiences with stigma, I will look closer into the journeys of three select individuals – Phindile, Bhekesisa, and Betty. These

[163] Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963. 149.
[164] Green, Gill and Sobo, Elisa J. *The Endangered Self: Managing the Social Risks of HIV*. London and New York: Routledge, 2000. 15.

three reveal their experiences with this type of 'internalised stigma' in their narrative and photographs while demonstrating an embrace of the photographic process as a tool of resistance. In his essay "Photography and AIDS," Simon Watney discusses how photographers can be part of the 'resistance' movement:

> Photographers are particularly well positioned to interrupt the constant flow of images that conflate HIV and AIDS and to challenge the rude and cruel version of the epidemic that continues to regard AIDS as a moral verdict rather than a medical diagnosis.[165]

Although we have to consider that Watney is speaking from his knowledge of images in the West, the experience with stigma in South Africa is significantly premised on the issue of morality and immorality. For the *TPE* project, the 'positioning' of photographers is crucial when the photographers are themselves capturing the images of HIV and AIDS they wish to represent for themselves and of themselves to challenge the stigmatizing associations. With the cameras in the hands of the person living with HIV/AIDS rather than being depicted through another lens, these individuals actively contribute to a paradigm shift in portrayals of HIV/AIDS. Within the framework of the *TPE* initiative, people living with HIV/AIDS must be at the forefront of altering the current of injustice and stigma with their stories of survival; treatment has changed the trajectory of the virus and therefore, it is also time to change the perception of HIV-positive human beings.

[165] Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 75. [Essay first published 1988.]

Figure 29: *Phindile's Self-Portrait.*[166]

[166] Phindile. *Phindile's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

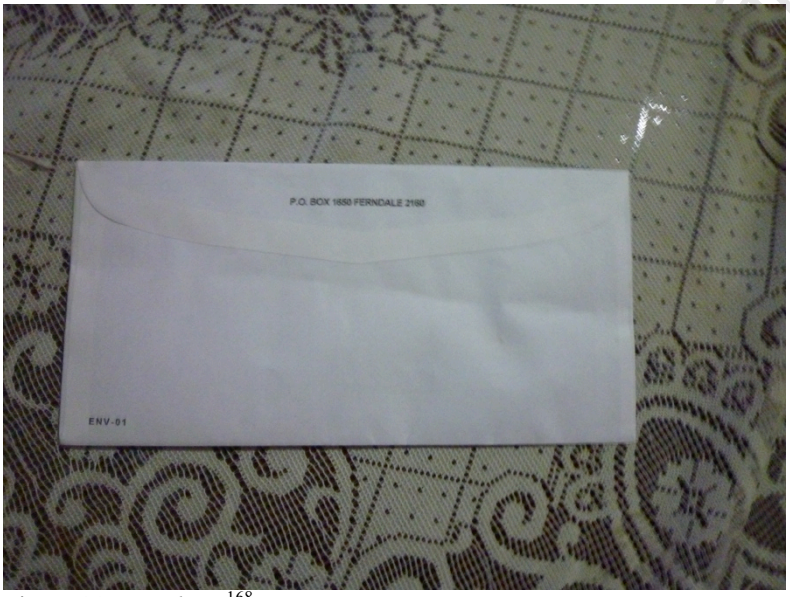
Each to His Own Mountain: Destigmatising the Mind through Photography

Living with HIV/AIDS can result in an individual beginning to feel that his identity is no longer multi-faceted and that the only aspect worth noting is that of their HIV status, a stigmatised status. In many instances, I have even heard people speak as if they are their HIV in an identity conflation of the virus with the self. In his critical analysis of language, Kenyan writer Ngũgĩ wa Thiong'o distinguishes the terms 'colonised' and 'decolonised' mind in a discussion on the impact of enslavement and degradation on black Africans. In South Africa, Steve Biko concurred with Ngũgĩ's thesis and developed "Black Consciousness," where he deemed the mind to be a 'weapon' in the struggle for freedom from oppression: "At the heart of this kind of thinking is the realization by blacks that the most potent weapon in the hands of the oppressor is the mind of the oppressed."[167] In my discussion of de-stigmatisation in this chapter, I take Ngũgĩ's theory a step further by applying it to stigma – the 'stigmatised' and 'de-stigmatised' mind. Just as the colonised mind was infused with a sense of shame and worthlessness due to a domineering political, social and cultural agenda, the stigmatised mind experiences the same. The idea is that the mind itself becomes 'colonised' so that even once power is no longer wielded physically, mentally it is significantly more difficult to remove oneself from an oppressive state. As with colonization, stigmatisation is internalised and in HIV/AIDS, this internalization also bares the shame of previous degradation. While *Through Positive Eyes* does not claim to completely remove all stigma that exists within, its process facilitates individual development of new tools to help challenge the internalised stigma that is often deeply ingrained. *TPE* also aims to cultivate empathy through public exhibitions as a contestation of the social stigma that further encumbers individuals' internalization of stigma. But first it is imperative to understand the significance of the *TPE* process as a transformative experience for the HIV-positive individuals involved. In contrast to the sensationalized, prevailing images of death and suffering that have engulfed the HIV/AIDS

[167] Biko, Steve. "Black Consciousness and the Quest for a True Humanity." *I write what I like*. Northlands: Picador Africa, 2004. 101-02. [Originally published in 1978.]

pandemic and even moreso of the 'African' context of HIV/AIDS in the West, the compositions of photographs and narratives created by the seventeen participants contribute to a shift in the paradigm of HIV/AIDS representation of which I explore three in this chapter.

Self-representation emerges as multiple aspects of the narrators' identities are revealed. By depicting their lives with all of their complexities – their challenges of the present alongside their dreams for the future – they are effectively affirming that they are South Africans *living* with HIV/AIDS and that their *lives* must be acknowledged. But acknowledged by whom? There is certainly significance in feeling acknowledged by another, but moreso in acknowledging one's own self-worth and recognizing that one's own experiences hold value. Through this self-documentation of their *lives*, they themselves become human models for destigmatisation in South Africa and on a larger scale, as part of the global *TPE* initiative to combat stigma in its lobby for the rights of people living with HIV/AIDS.



When she went home and opened the envelope, all she found was, 'We are sorry, we are no longer going to take your blood. You can go and see the doctor.'

- Phindile

Figure 30: *Envelope.*[168]

Emerging from this photograph of a plain, white envelope is a narrative where the witness to Phindi's[169] story learns the significance of this envelope; it has been opened and re-sealed again and again and she has kept it since 1997. After going for her routine blood donation, Phindi spiralled into a discovery of her HIV-positive status after receiving this unsolicited, ambiguous envelope

[168] Phindile. *Envelope*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[169] Age 38, Living with HIV for 13 years, 1694 Photographs

with a letter inside advising her to see a doctor. She went multiple times to the local clinic to get tested where she said, "the counselling was not up to standard," and the counsellor told her that if "after two weeks they don't give you your results, that means you are HIV-positive." After a series of visits to the clinic and results being lost or unknown, she finally learned of her HIV-positive status and immediately began to withdraw and isolate herself from friends and family:

> When I arrived at home, I started isolating myself from the family in the house. I used to stay in bedroom most of my time. I was spending my time in the bedroom because I was afraid of listening to the news, watching TV. Because I know that if I'm watching the news there will be this red AIDS ribbon, or they are going to talk about HIV and AIDS then. I was affecting me, even if I'm in the taxi, I know that I will see a poster with HIV or AIDS. So, yeah, it affected me, Even though I didn't cry. I kept my status a secret for four years. No one knew in the family.[170]

Phindi's experience with internalising her stigma through her fear of having her 'secret' discovered is representative of many other women in South Africa. Although men also experience fear, women in particular experience an intense fear of disclosure and discovery of their status. Many South African women are economically dependent on their husbands (or partners or 'sugar daddies') so the fear of being abused with retributive violence or cast out from their homes substantiates this endemic distress especially because many of them lack the education to become economically independent from the men in their lives.[171] Phindi expresses her fears when she describes her disclosure for the first time to her mother,

> Then on Sunday when she was from church I said to her, 'You know what, mom, you don't have to cry. I've been living with this disease for four years now, and you can look at me, I'm healthy.' Then she said to me, 'Why you keep it a secret for so long?' And I said, 'I was afraid that maybe you are going to chase me away of your house, or whatever reason. So that is why I kept it a secret. But I wanted to tell you, but I didn't know how.' Then she hugged me and said, 'I love you, you are still my daughter.' You see?[172]

Phindi was fortunate to have such a supportive mother, but she also speaks of the friends and relatives that she lost along the way post-disclosure. Ironically, "some of the people I've buried

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[170] Phindile. *Through Positive Eyes South Africa*. Interview. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 2.
[171] "Gender-based violence." *UNICEF South Africa – HIV and AIDS*. n.d. Web. Available: http://www.unicef.org/southafrica/hiv_aids_729.html. [1 February 2012]
[172] Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 8.

were [the ones] laughing at me, saying some nasty words,"[173] she states. In this instance, Phindi twists social stigma on its head as the stigmatisers became the stigmatised. While she "used to cry when they say those things," she proclaims herself "a free woman"[174] now as she no longer reacts or is as sensitive to ignorant commentary.

Phindi's narrative strengthens my claim: Ngũgĩ's concept that 'decolonising the mind' can counter the 'cultural bomb' is applicable to my notion that 'de-stigmatising the mind' can counter denialism and stigma. While colonisation had an obvious impact on the local economies and politics, Ngũgĩ wa Thiong'o believes the "biggest weapon wielded" was what he calls the "cultural bomb":

> The effect of a cultural bomb is to annihilate […] a people's belief in their environment, in their heritage of struggle, in their unity, in their capacities and ultimately in themselves. It makes them see their past as one wasteland of non-achievement and it makes them want to distance themselves from that wasteland. […] It makes them identify with that which is decadent and reactionary, all those forces which would stop their own springs of life. It even plants serious doubts about the moral rightness of struggle. Possibilities of triumph or victory are seen as remote, ridiculous dreams. The intended results are despair, despondency and a collective death-wish.[175]

In the same way the colonial 'cultural bomb' threatened to disengage people completely, this modern day 'bomb' endangered the confidence in survival of those living with HIV particularly 'in their 'capacities' and 'in themselves'. In spite of Sontag's critique of metaphors of war used in relation to illness, I cite Ngũgĩ's use of the 'bomb' metaphor to emphasize the correlation I make between his point and my own. As I stated in chapter one, I agree with Sontag that it is not ideal to speak of illness in metaphor particularly metaphors of war as this can also generate stigma, but I find Ngũgĩ's concept of the 'cultural bomb' essential to understand the way in which stigma incapacitates an individual's sense of self-worth. In his *Ways of Seeing,* John Berger also alludes to this perpetual relationship between "conqueror and colonised," where "the sight of the other

[173] Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 8.
[174] Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 8.
[175] wa Thiong'o, Ngũgĩ. "Introduction." *Decolonising the Mind: The Politics of Language in African Literature.* Oxford: James Currey, 1986. 3.

confirms each in his inhuman estimate of himself,"[176] and I contend that the relationship between stigmatiser and stigmatised is caught up in the same cycle. Challenging institutionalised, structural stigma is extremely difficult, and it is clear that external influences have a potent effect on the private, internalised stigma. When a government appears callous towards a group of already marginalised people, ensuing 'despair [and] despondency,' as Ngũgĩ writes, is inevitable. While Phindi's own process of 'destigmatising' herself began with her initial disclosure, it has carried her to the top of Kilimanjaro, a pinnacle moment in her healing process and into the arms of a loving fiancée. In group sessions, she passionately discussed both and adamantly wanted to include related images as part of her *TPE* self-portrait to contest the prevailing association of HIV with death and present herself as *living* with HIV and *living* vibrantly.

Figure 31: *Phindile and Fiancee.*[177]

It is this photo that Phindile chose to be her signature photo for her self-portrait. In the process of selecting photos, each individual worked with one photographer to narrow the hundreds, and sometimes over a thousand photos, down to a range of 20 - 30 photos – this was based on technical quality and aesthetics and the focus of the narrative the individual wanted to share. Then the group came together for group editing sessions, where the group collaborated with the individual to select

[176] Berger, John. *Ways of Seeing*. London: Penguin Books, 2008. 49. [Originally published in 1972.]
[177] Phindile. *Phindile and Fiancee*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

twelve photographs that would be on the final posters. And finally, the individual photographer selected the photograph that would be their signature photograph. There were challenges during this selection process, even controversy, which stirred sometimes between participants and sometimes between facilitators and participants. This usually happened either when a photograph was not as aesthetically or technically strong but was extremely significant to the individual who took it or when the group disagreed as to whether the photograph conveyed something that bothered them even if it was not their photograph. While there were a few discussions where this happened, the one discussion in particular where the group's emotional intensity heightened was concerning disclosure of the HIV-status of children. The question whether children under the age of 18 could give their permission for images to be used which may possibly disclose their HIV status or whether their parents could make the decision on their behalf or whether neither should happen was passionately debated. One of the participants felt the need to share his child's experience being positive as part of his own and there was a split response in the group. Some felt that it was in his jurisdiction to decide what photographs to use and what story to share, and others felt that every individual, regardless of age, has the right to disclose his respective status at a time of his choosing. Some of the children who were positive wanted to be open with their status as part of their parent's self-portrait but the parents disagreed. The image selection process is certainly worthy of further discussion because every image captured has significance. Whether the photographer's decision is conscious or subconscious to capture a particular image, there is an aspect of invisibility to the stories as it is not possible for everything to be included – photographs share the features of transparency and ambiguity. According to sociologist and oral historian V. Yow, sharing a life story narrative is inherently selective for "nobody tells another person everything"[178] but similarly, photographs are also selective on the part of the photographer and of the witness: "Any photograph has multiple meanings, indeed, to see something in the form of a photograph is to encounter a

[178] Yow, V. *Recording Oral History, A Practical Guide for Social Scientists*. London: SAGE, 1994. 172.

potential object of fascination,"[179] where what is seen and the meanings derived change with the context. But ultimately, each participant had agency with final decision-making power over his or her own photographs, narrative and overall aesthetic.

As seen in Figure 32, Phindi was one of the participants who clearly articulated what she wanted to portray and the vehemence with which she declared this image to be her signature photo is noteworthy. She allowed for brief discussion with the facilitators and the group about the photograph, but she had decided before entering the space what she wanted to include in her self-portrait poster. The setting of the photo is just as important to her as the subject; it is in her home:

> I feel great about my home, because I was born there, I grew up there, and I'm still there. [chuckle] I'm still there with my fiancé. […] I love that home.[180]

The way in which she repeats, "I'm still there. I'm still there with my fiancé" and chuckles with a smile in between exudes a tone of persistence not just about living in her home but about 'still' being alive. This reminded me of one of the Los Angeles posters entitled 'Still Here'[181]; this emphasis on living and surviving continues to be revealed in the *TPE* pieces. In spite of the challenges she faces externally, Phindi takes on her internal burden with spirit and resolve. Womens' studies professor Gabriele Griffin speaks of a fascinating concept she names "surviving corporeality," and this is what is expressed in Phindi's narrative and images; that despite the virus in her blood, she is optimistically *living* with HIV and all of its complexities. Griffin describes this capability of "surviving corporeality" as

> *...living with* our bodies , whatever shape, colour, form, identities these take…despite rather than because of ourselves…while the body has remained marked as stricken by disease, it has in fact outlived epidemics and continues to exist beyond the moment of marking.[182]

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[179] Sontag, Susan. *On Photography*. London: Penguin Books, 2008. 23. Originally published in 1977].

[180] Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 5. [From Sound Clip 20:21 – 20:31].

[181] Wilson, Phil. *HIV-Positive in Los Angeles: Twelve Stories*. 2007. Web. Available: http://artsci.ucla.edu/hivla/phill/index.html. [1 February 2012].

[182] Griffin, Gabriele. "Introduction." *Representations of HIV/AIDS: visibility blue/s*. Manchester: Manchester University Press, 2000. 9.

In a way, the process – the storytelling, the group sharing, the image capturing – contributes to the destigmatisation of the mind while the product – the self-portrait – contributes to the destigmatisation of the body. The latter is apparent in Phindi's photo where the subject is of her and her fiancée kissing in bed, which she candidly describes in this way,

> I think that to be HIV-positive doesn't change your sexual behavior or what. The only bad part of it is just that you have to put a condom every time you want to have sex. But for foreplay and everything else, it's nice and it gives me a positive mind. People, they think that if you are HIV-positive you don't have family, you don't have a boyfriend or girlfriend, you don't get married…But to me, I told myself that HIV is just a virus which is in my bloodstream but it cannot change my dreams…[183]

This statement reveals that she is not evading the difficulty in being sexual with her partner and needing to wear a condom every time they have intercourse, but she is also very firm and open about the possibilities of sexuality as an HIV-positive woman. Phindi is not only the photographed but the photographer – the main principle for *TPE* as a process of personal development – and as photographer she establishes her presence as a sexual woman despite her HIV-positive status. Sander Gilman writes about how the "erotic body, no matter what its actual status, remains associated with the healthy, not with the dead or dying."[184] But here Phindi's 'erotic body' is juxtaposed with text detailing her sero-positive status, thereby resisting the pre-existing impression of what a 'healthy-looking body' means and what an 'HIV-positive body' should look like in a dance of disparity. What then does this mean when the 'erotic body' is that of the 'unhealthy person? With the extent of HIV/AIDS stigma due largely to its affiliation with its mode of transmission – sex! – individuals living with HIV are categorized as 'promiscuous' or 'sexually immoral'. Yet here, Phindi is very blatantly stating – 'Here I am – HIV-positive and a healthy sexual being and let's not forget an African and a woman too!' – Now what is made of the pre-established social boundaries between 'self' and 'other' when a new conception of 'self' and 'other' is created? What was the "'feminised' Other… passive but pathetic objects capable of offering

[183] Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 6.
[184] Gilman, Sander L. *Health and Illness: Images of Difference*. London: Reaktion Books, 1995. 120.

themselves up to a benevolent, transcendent gaze – the gaze of the camera and the gaze of the paternal state,"[185] is changing to reflect individuals like Phindi who celebrates her repudiation of this assertion. Cultural and political commentator Judith Williamson assesses how the threat of AIDS is linked to the "*breakdown* of boundaries [as] the virus threatens to cross over that border between other and Self: the threat it poses is not only one of disease but one of dissolution, the contamination of categories."[186] This crossing of boundaries is what people fear as the individual's imagined invincibility is challenged by the presence of HIV/AIDS. Through public engagement in a visual encounter with the self-portraits, openly exposing the crossing of boundaries is precisely what *TPE* sets out to do. Across the four cities that have thus far participated including Los Angeles, *TPE*'s participants span age, race, religion, ethnicity, nationality, language, gender, and sexual orientation. *Through Positive Eyes South Africa* is an arts-based model for demonstrating this 'cross over' between 'other and Self' as it aims to demonstrate the interchangeability of this binary when HIV/AIDS enters the framework. Clearly revealed in her self-portrait, Phindi empowers her 'other'ness – specifically being HIV-positive – as she does not negate its existence but affirms there is more to her identity than just HIV. In light of the fact that access to ARVs was minimal, Watney states in 1988 that there is no hope for a person with AIDS to "enter the public space of photographic representation save as a sign of mortality."[187] As I expressed in chapter one in my discussion of Gugu, it is important that thirty years later, this representation Watney speaks of is not omitted completely but that it is not the only representation. By choosing to portray herself *living* with HIV, Phindi provides an empowered proxy to the media's 'wretched of the earth' melodrama on automatic replay. It is the same "ongoing struggle" Watney speaks of in the early years of the epidemic,

[185] Tagg, John. *The Burden of Representation: Essays on Photographies and Histories*. London: The Macmillan Press, 1988. 12.
[186] Williamson, Judith. "Every Virus Tells A Story: The Meaning of HIV and AIDS." *Taking Liberties: AIDS and Cultural Politics.* Eds. Erica Carter and Simon Watney. London: Serpents Tail, 1989. 78.
[187] Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 65. [Essay first published 1988.]

> …between the deeply embedded cultural picture of AIDS as retribution and a model of health which suggests the possibility of individuals and whole social groups taking control of the circumstances and definitions of health and disease.[188]

While it still continues today, gradually the shift in representation is encouraging individuals to hold the reins of their health, and *TPE* is one initiative that partakes in this shift through narrative and photography. Individuals like Phindi prove that a change towards a new, living, active self-representation makes the process of destigmatisation more possible.

[188] Watney, Simon. "Photography and AIDS." *Selection of Essays.* Durham: Duke University Press, 1994. 65. [Essay originally published 1988.]

Figure 32: *Bhekesisa's Self-Portrait.* [189]

[189] Bhekesisa. *Bhekesisa's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center. NOTE: As of the final print of this thesis, it is important to note that Bhekisisa and his wife are no longer married but she is still incredibly supportive of him. He is still optimistic

Until Death Do Us Part: A Changed Man

While the emphasis of the HIV/AIDS pandemic is commonly placed on women, particularly the necessity for women empowerment, it is just as important to spotlight men living with HIV. One example of this is South Africa's Sonke Gender Justice Network's "Brother 4 Life" campaign, which aims to educate men around human rights issues, on their own sexual health, and establish an acknowledgement of the scope of their influence in their families and communities.[190] Advocating for men to be positive decision-makers for their families' well-being while also encouraging men to want to be active and responsible husbands and fathers in a country where there is a general lack of male involvement in family health issues is a huge advance in the South African world of NGOs which tend to focus on women and children. While by no means a justification, it is important to consider why men have not been generally involved in family health issues. The urbanisation of the male workforce and thus the separation of men from their families is part of apartheid's legacy in South Africa - this reality is a repercussion of Farmer's "structural violence." I find that the 'black man''s disconnect from his family is interrelated with his disconnect from himself. In 1978, Steve Biko described this disconnect when he wrote,

> …the type of black man we have today has lost his manhood. Reduced to an obliging shell, he looks with awe at the white power structure and accepts what he regards as the 'inevitable position'. […] All in all the black man has become a shell, a shadow of man, completely defeated, drowning in his own misery, a slave, an ox bearing the yoke of oppression with sheepish timidity.[191]

Even though Biko is writing in the midst of the apartheid era, the content of what he says is still relevant today. To relate a 'black man' to 'an obliging shell' infers an emptiness inside without agency. By including this, I am not implying that every 'black man' today recognizes this sentiment as strongly as Biko did then, but it is essential to acknowledge that these feelings of

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about finding love as an HIV-positive man. "All people must have hope for love. You can still live your life to the fullest." – May 2012

[190] "Brothers for Life." n.d. Web. Available: http://www.genderjustice.org.za/index.php/projects/brothers-for-life. [1 February 2012].

[191] Biko, Steve. "We Blacks." *I write what I like*. Northlands: Picador Africa, 2004. 29. (Originally published 1978.)

defeat and inferiority, similar to Ngũgĩ's 'colonised mind,' can be understood as trans-generational trauma and can end up having an impact on a man's relationship with his family. In the same vein that I claim the facilitation of de-stigmatisation, it is through therapeutic processes like *TPE* that individuals gain strategies to empower themselves physically, emotionally and mentally.

In *TPE South Africa*, of the 17 participants, 7 were men, which is quite an impressive statistic in a country where greater emphasis is often placed on the women's burden of HIV and stigma. Even so, it is important to acknowledge that men are also impacted by the blame-game in South Africa and its role in the progression of HIV/AIDS stigma. In his book, *AIDS and Accusation*, Paul Farmer explains that particularly in the developing world, "Blame has played an important – and often destructive – role in social responses to AIDS..."[192] and the scapegoats of this blame have been shamelessly confronted with the stigmatic imprint of HIV/AIDS.

There is no doubt that black women experience the "double burden of race and gender," and with the additional burden of HIV, it is referred to as the "triple jeopardy faced by African women,"[193] but it is essential for all who aim to de-stigmatise HIV to recognize that "when it comes to HIV in South Africa, gender discrimination has not been restricted to women."[194] It is valid to say that women are probably more likely to seek treatment due to pregnancy and available PMTCT programs but it is only when the country finds that men are as aware of their health as women that the culpability of men is distanced and this gender distinction will become less stark. Of the seven men who shared their presence with the *TPE South Africa* group, I highlight one – Bhekesisa.

Bhekesisa[195], or Bheki, applied the tools learned during the *TPE* process to create a representation of his own self-awareness and transformation to become a "family man." The lasting

[192] Farmer, Paul. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press, 1992. 229-230.
[193] Karim, Quarrisha Abdool. "Heterosexual transmission of HIV – the importance of a gendered perspective in HIV prevention." Karim, S. S. Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008. 255.
[194] Wilson, Douglas and Fairall, Lara. "Challenges in managing AIDS in South Africa." Karim, S. S. Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008. 489.
[195] Age 34, Living with HIV for 9 years, 1092 Photographs

effect of Bhekesisa's story is his focus on his relationship with his wife and his children, particularly his youngest little girl, their daughter. Throughout the thirty years of the HIV/AIDS epidemic, the pervasive fear of sexuality continues as HIV, sex and death became conveniently intertwined. As a result, after discovering an HIV-positive diagnosis, individuals tend to believe that a meaningful relationship is not possible, and certainly, not one with an active sex life. This initial perspective is evidenced by group discussions and interviews where several participants decided to share about their anxieties and challenges of getting involved in relationships.[196] As manifest in his photographs, Bhekesisa is one of the participants who challenges the misconception that an HIV-positive person has no possibility for love in life after being diagnosed. While his relationship is serodiscordant, some participants shared different experiences being in sero-concordant relationships. Based on their study of analysing social risks of HIV, medical sociologist Gill Green and medical anthropologist Elisa Sobo discuss the process through which HIV-positive individuals "come to believe that they are indeed dirty, dangerous, and undesirable," a self-stigma which impacts heavily on one's hope for being in a real relationship.[197] But the photographs we see from Bhekesisa eloquently alters the image of the lone, HIV-positive individual with images of a sero-discordant couple, living and loving.

[196] Group Discussion in *Through Positive Eyes South Africa*. Johannesburg: Make Art/Stop AIDS. 2 March 2010.
[197] Green, Gill and Sono, Elisa J. *The Endangered Self: Managing the Social Risks of HIV*. London and New York: Routledge, 2000. 192.

Figure 33: *Family Portrait.*[198]

Figure 34: *Kissing Mama.*[199]

Figure 35: *Kissing Daddy.*[200]

> She my wife, she's more supportive and she's very very sensitive. So when it comes to issues of health, she tried to give me a lot of support. […] Sometimes I used to say she's doing it maybe for the love that she had for me because she want me to be strong enough to live long, to sustain my life for a long time – until death do us part… I can say I was lucky to have a woman that loves me so much, you know, not hesitating to people's talks. [201]

Bhekesisa and his wife had been married for nearly 3 years when he participated in *TPE South Africa*, and his familial images are a perfect example of how the *TPE* process undeniably advances the changing lens of HIV/AIDS in representation. For example, in Figure 33, a family photograph of Bheki, an HIV-positive husband and father, his wife, an HIV-negative wife and mother, and their

[198] Bhekesisa. *Family Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[199] Bhekesisa. *Kissing Mama*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[200] Bhekesisa. *Kissing Daddy*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[201] Bhekesisa. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 12 March 2010. 3.

HIV-negative baby girl, achieves what the likes of Watney and Sontag challenged in HIV/AIDS representation in the beginning years of the pandemic. While these images demonstrate what can now be a realistic possibility for an HIV-positive individual living today, what stands out in Bhekesisa's story is his pressing desire to share his initial experience of self-stigma, having himself been the individual who equated HIV with his life being over. He relays this as he explains why he took a series of photos at a cemetery and burial site:

> People must understand that when you're positive, it's not the end of the world. […] You know, I want people to understand that it's a fact everyone is going to die, whether we are HIV-positive or not... We as black people, we used to bury people at weekends, Saturdays and Sundays. But if you look at these days now, since the HIV/AIDS issues come in our lives, you know, we bury people each and every day. It shows that people they are still maybe in denial of this disease, you know. Discrimination is still there. It's a fact: we can't run away from death. When death comes it comes, but now we don't have to relax and say, "Because I'm positive, I'm already dead." No! If you are positive, you can still live your life to the fullest.[202]

Figure 36: *Cemetery*.[203]

Figure 37: *Burial Site*.[204]

On the one hand, it is important that Bheki includes these images because they reflect the reality that people are still dying from HIV/AIDS in South Africa, and this, over a decade since Gideon Mendel took his images of the funerals in the Copperbelt of Zambia as seen in Figure 7. Although these images might at first seem to associate death with HIV/AIDS, the way Bhekesisa explains his reason for taking these photos is that while he does not want to deny death, it does not have to be at

[202] Bhekesisa. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 12 March 2010. 4.
[203] Bhekesisa. *Cemetery*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.
[204] Bhekesisa. *Burial Site*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

the forefront of one's mind if diagnosed HIV-positive. He also agrees that denial of the epidemic still exists, fostering the social stigma that persists in South Africa.

Considering that a common goal for the *TPE South Africa* group was to combat stigma, one unique challenge occurred during the group edit where a part of Bhekesisa's narrative triggered a sense of stigma by others in the group. While it was often the women who tended to view themselves as predominantly stigmatised, the tables were turned by the women in this particular situation with Bhekesisa. We began to discuss the Figure 38 photograph, and one of the women asked about the boy in the photograph:

Figure 38: *Soccer Player.*[205]

Bhekesisa openly spoke about his children, and on coming to this photo, he said it was one of his children from a different mother, and he then disclosed that he had a few children from different mothers before he married his current wife. This caused heightened emotions in some of the women in the group to the point of labeling Bheki a 'player,' and freely releasing comments that would definitely be considered verbal abuse. As I had interviewed Bheki previously to this group blow-up, I knew that this was a part of his past but not a part of his present. A strong wave of uneasiness overcame me as I watched closely to see how he would respond to the reaction. But Bhekesisa took it in stride, and he paraphrased to his peers what he had said to me in his interview:

[205] Bhekesisa. *Soccer Player*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

> I had many girlfriends. I was just a playboy. But after testing I realized I have to change. I asked many questions after testing. How can I survive? […] I tell myself that now it's time for me to change… It's time for me to change because I really want to live and then I really love life. That's why I started to change my life.[206]

In this instance, the group confronted HIV-positive on HIV-positive stigma and this scene could have significantly ruptured the group's 'safe space'. But in the moment, the group transcended their own stigmatised perspectives to see Bheki the 'player' return to being Bheki the 'husband and' Bheki the 'father' that they had grown to connect with throughout the *TPE* process. The product seen in Bheki's family photos is the result of Bheki's own process of de-stigmatisation.

> I'm a loving, caring person… As a father, I saw that it's important to take care of my children. And, yes, my father didn't take care of me, because of my father's many wives, you know. But I realized that I'm the only child who I can say maybe I just look like my father, the behavior, everything. But now, as I've said, since I've- I've realized that I'm positive, I saw that it's important to change my life completely, to think positively, you know, to take care of everything, to- to rectify all the mistakes that I've done in my life.[207]

Bhekesisa confronted the social stigma by the group toward having multiple concurrent partners; and the group was privy to engage in empathetically listening to his process of 'de-stigmatisation' in an open, honest way while simultaneously confronting their own stigma against having multiple partners. As the son of a father who had many wives, having multiple partners was part of his 'normal' framework, and therefore Bheki not only had to transcend the social stigma but reconcile his decision to be monogamous with his familial traditions. It is this interaction that highlights the poignancy of engaging with the presence of a real person. It is essential to recognize this when analyzing the encounter with the self-portraits by an unaffiliated individual who confronts the photographs and narrative for the first time as opposed to the group who has been interacting closely with the actual people on a daily basis. Speaking about her work with the Bambanani Women's Project in an article "Selling Sorrow," Kylie Thomas, referring to the women's body maps, points out,

[206] Bhekesisa. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 12 March 2010. 1.
[207] Bhekesisa. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 12 March 2010. 6.

> …the popular appeal of these self-portraits is connected to how they have been cast as sites of authenticity, points of access to the real. The ways in which the portraits were produced and the ways in which they have been circulated and interpreted has been premised on the idea that their subjects can be known, not only by the artists themselves, but also by those who view them.[208]

It seems there is a general acceptance that when images, particularly portraits, are encountered, the portraits are interpreted as authentic portholes to engage with the people in the images. But with the absence of the physical person, as evident in witnessing Bhekesisa's final self-portrait in Figure 32, it is impossible to gauge a complete understanding of this individual's life story. This is validated by the fact that, for example, the encounter with Bheki's poster has no context for the controversy that transpired during the group editing process. On the other hand, the encounter does contribute to overcoming stigma as it fosters a space for empathy. This is the essence of what the *TPE* encounter strives to achieve. Echoing David Gere, *TPE* offers an experience for "an observer to increase his range of empathy by appealing to the human aspect of 'Ubuntu'"[209] as the observer bears witness to the self-documented images of the HIV-positive individual in the self-portrait poster.[210]

Bheki's signature photograph, as seen in Figure 32, sets the scene for Bheki's narrative. This photograph draws the observer from the outside room through the curtains into the bedroom where Bheki's little girl is fast asleep. In my interpretation of this photograph, it highlights the contrast between the misconceived asexuality of an HIV-positive individual with the embodiment of a fruitful sexual encounter – a child – all in the center of sexual activity – the bedroom. In the smaller of the two signature photos, the image of Bhekesisa and his wife in an embrace epitomizes his rejection of all the opinions he has been subjected to about the non-existence of love for an HIV-positive individual. In this way, through his newly acquired photographic skills and creativity,

[208] Thomas, Kylie. "Selling Sorrow: testimony, representation and images of HIV-positive South African women." *Social Dynamics* 34.2 (September 2008): 219.
[209] Gere, David. "Drama for Life Festival Keynote." University of Witswatrsrand. August 2011. Lecture.
[210] Ubuntu is an African philosophy of humanity and its essence is that we are all part of a greater whole and so the way people treat one another must be with dignity and respect to uphold that interconnectedness of being human. "Ubuntu." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Ubuntu_(philosophy). [5 September 2012.]. 1.

Bhekesisa powerfully portrays exactly what he wishes to emphasize in his images, thereby empowering his own contribution to the shift in representation of South Africans living with HIV. Ngũgĩ wa Thiong'o comments on the distinction between the imaginary and the real and the human ability to bridge these through artistic means:

> Our whole conception of ourselves as a people, individually and collectively, is based on those pictures and images which may or may not correctly correspond to the actual reality of the struggles with nature and nurture which produced them in the first place. But our capacity to confront the world creatively is dependent on how those images correspond or not to that reality, how they distort or clarify the reality of our struggles.[211]

This is the essence of what *Through Positive Eyes* strives to achieve. Echoing what David Gere described in a keynote speech at the University of Witwatersrand Drama For Life Theatre Festival in August 2011, *TPE* offers an experience for the observer to increase his/her range of empathy by appealing to the human aspect of "Ubuntu" in an encounter with the achievements and challenges of living with HIV.[212] Of course, there will be the observers who simply feel they find no connection and others who will not even engage with the pieces but by publicizing these self-portraits, I ascertain that the encounter can contribute to the "overcoming of stigma" by the observer via an empathetic forum. Reflecting on Bhekesisa, it is important to recognize that the encounter with the poster does not render a complete, authentic picture of the individual as there are many things left concealed for example, the controversy that happened during the group edit in Bhekesisa's case. But ultimately, the encounter with the visual narrative does convey aspects of his identity that in bearing witness, facilitates a connection between him and the observer.

[211] wa Thiong'o, Ngũgĩ. "The Language of African Literature." *Decolonising the Mind: The Politics of African Literature.* Oxford: James Currey, 1986. 15.
[212] Gere, David. "Drama for Life Festival Keynote." University of Witswatrsrand. August 2011. Lecture.

Figure 39: *Betty's Self-Portrait*[213]

[213] Betty. *Betty's Self-Portrait*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

Disclosure and Stigma: Her Body, Her Own Way

While each individual travels his or her own journey through diagnosis with his/her own unique challenges and difficulties, experiences with stigma continue to re-emerge in the stories of the 17 *TPE* members, symbolic of the general experiences of HIV-positive people living in South Africa. One such narrative is that of Betty,[214] whose story reveals itself differently as compared to the others:

> I was scared. I tell my mother lyings. […] I started getting treatment in Baragwaneth. I'm going private – alone – because I don't want people to see me. This why I got driven from Germiston to Baragwaneth because I don't see people to see me where I'm going – that I'm going for this treatment.[215]

Betty begins her narrative speaking about her intense fear of disclosure, and the cloak of secrecy inside which she was enveloped to prevent anyone from finding out, especially her mother. When she emphasizes "I don't want people *see* me – I don't want *see* people to *see* me," it is apparent how intense her experience of stigma was in South Africa in the early nineties. In an essay on the impact of AIDS on South African communities, stigma's prominent role in conjunction with the pre-existing prejudice is highlighted:

> Stigma is an insidious, complicated phenomenon that feeds upon and reinforces and reproduces already present inequalities of class, race, gender and sexuality. In South Africa…stigma has gone hand in hand with discrimination.[216]

While Betty's journey from this early stage in her post-diagnosis, positive life was charged with fear, stigma and secrecy, her narrative alters course to reveal a stronger, more confident self as she finally decides to disclose to her mother, to her family, and to close friends. To combat this internalised stigma of the mind is an ongoing process of self-reconstruction. Steve Biko's 'Black Consciousness' ascertains that liberation of the mind is a necessary process to resist the repercussions of the mental subjugation of the colonial aftermath and apartheid. The crux is that individuals need to journey through this process on the road toward attaining "the envisioned self

[214] Age 37, Living with HIV for 20 years, 669 Photographs
[215] Betty. *Through Positive Eyes South Africa*. Interview. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 2.
[216] Frolich, Janet. "The impact of AIDS on the community." Karim, S.S. Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008. 354.

which [ultimately] is a free self."[217] By redefining the way Betty sees herself, she resists the prejudices imposed on her as an HIV-positive South African black woman and she brings to the fore a new image of HIV in South Africa. In the same way Steve Biko terms this "inward-looking process," the first step of Black Consciousness, in Betty's case – this disclosure was an all-in-one first step towards Black Consciousness, Female Consciousness and Seropositive Consciousness as she aims "to pump back life into [her] empty shell; to [re-]infuse [her] with pride and dignity,"[218] transcending the paradigm of stigma through her narrative and photography. As Betty explores herself through the lens of her camera, her focus on her body image demonstrates her newfound self-confidence:

> For my body, I love my body. Once I've touching, I've get happy. I know and sit in the mirror. I tell myself I'm Betty. I want somebody see me funny. Me, I trust myself. Here's my body.[219]

When considering the vast array of negative images reflected on HIV-positive people of themselves or of what others think of them, it is extremely significant to hear the way Betty speaks of her body and see the way she chooses to capture her body in photographs.

[217] Biko, Steve. "The Definition of Black Consciousness." *I write what I like*. Northlands: Picaor Africa, 2004. 34. [Originally published in 1978.]
[218] Biko, Steve. "We Blacks." *I write what I like*. Northlands: Picador Africa, 2004. 31. [Originally published in 1978.]
[219] Betty. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010. 6.

Figures 40 - 43: *Turquoise Gown Series*[220]

In this series, Betty utilizes the self-timer feature on her camera to self-reflect different body positions in bed, wearing a silky turquoise nightgown. In reading these photos, I see Betty choosing to photograph herself in the way she thinks others expect to see her as an HIV-positive woman in South Africa – alluring, sexy, and in bed. But by taking the camera in her own hands, she is now claiming that representation as her own by feeding her own images into the trajectory of representation. As I discussed with Phindi, society links HIV/AIDS to connotations of sexual promiscuity and deviance but also to sexual emptiness as I discussed with Bhekesisa. In Figure 40, Betty looks straight at the camera, in a way asserting her presence, but then in Figure 41, something unique is captured. Betty has shifted the position of the camera so that it only gets a fragment of her body on the bed. In this photograph, the camera snapped a slice of her– where her gown meets the top of her leg, still emphasizing her sexuality. In Figure 42, her comfort with the camera is displayed as the focus is on her body but she looks away, letting the camera take her naturally and I

[220] Betty. *Turquoise Gown Series*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

find that in Figure 43, where she splits her legs, this once again symbolizes her reclaiming her own sexual identity as her, 'Here's my body' moment to herself in the camera. Although I will delve further into the significance of mirror reflection in the third chapter of this thesis, the poignancy of her declaring "I know and sit in the mirror. I tell myself I'm Betty" reveals a contemplative moment of reflection, building her confidence on who she is and what she is about. As Betty became more trusting of the process during the *TPE* arts initiative, this reflected a growing trust in herself – "Me, I trust myself. Here's my body." While Betty's "body" was a container for the HIV virus, she reclaims her body as her own, not just as an embodiment of the virus, in these images – "I'm Betty… Here's my body." As I wrote previously, it is not uncommon for an HIV-positive individual to see themselves as representations of the virus inside them. In their study on the impact of an HIV-positive diagnosis on identity, Green and Sobo cite participants who "often spoke as if infection with HIV is a state of being – 'I am HIV.'"[221] In many of her photos beginning with the workshop introduction to the camera and in her own experimentation with the camera, Betty's lens captured her body constantly.

Figure 44: *Betty in Green*[222]

Figure 45: *Betty in the Cushions*[223]

As discussed previously, self-construction and renegotiation of one's identity post-diagnosis is a complex ongoing process, but this is often further complicated by the "cultural expectations for personhood that they have internalised" in contrast with the "cultural connotation of AIDS and the

[221] Green, Gill and Sobo, Elisa J. *The Endangered Self: Managing the Social Risks of HIV*. London and New York: Routledge, 2000. 63.
[222] Betty. *Betty in Green*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.
[223] Betty. *Betty in the Cushions*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

practical consequences of being HIV positive."[224] As with many aspects of one's identity, HIV becomes a new facet that "s/he may integrate wholly, partially, or not at all, into a new sense of self."

Betty is a 37-year old South African woman, who began her journey unable to disclose to anyone; now, here she is participating in an arts initiative, opening up completely among peers during the group sessions, and speaking her mind forcefully through her contagious laughter and beautiful smile. She does still insist on the privacy of certain aspects of her life that have remained excluded from her self-portrait but she is present; she is here.

These 17 individuals participated in the project, they shared their stories, they captured photographs to represent their stories, some more open and some less, but they all appeared – physically and emotionally they had a presence. In his *Camera Lucida*, Roland Barthes develops the idea that "photography offers an immediate presence to the world – a co-presence [with the world] … Every photograph is a certificate of presence,"[225] recognizing the power 'presence' can have on an individual especially someone whose 'presence' has been disregarded. One cannot be denied presence in a photograph, and it is this presence that reveals a willing desire to allow *Through Positive Eyes* to be a chapter in their process of fostering acceptance of their status and destigmatising their mind and body. In the same vein that I explore the three self-portraits of Phindile, Bhekesisa and Betty to demonstrate the process of de-stigmatisation through photography, in the following chapter I will explore two more self-portraits by engaging with the metaphor of the 'mirror' and analysing it as a symbol of self-reflection and self-perception.

[224] Greem, Gill and Sobo, Elisa J. *The Endangered Self: Managing the Social Risks of HIV*. London and New York: Routledge, 2000. 192.
[225] Barthes, Roland. *Camera Lucida: Reflections on Photography*. Transl. by Richard Howard. London: Vintage Books, 2000. 87. [Originally published in 1980.]

CHAPTER THREE:
MIRROR ENCOUNTER: RECONSTRUCTING HIV/AIDS IN SOUTH AFRICA

…Africa is moving in several directions at once. This is a period that, at the same time, has been, is not yet, is no longer, is becoming – in a state of preliminary outline and possibility, The mirror reflects a figure that is in the present yet escapes it, that is, at once, in front and behind, inside and outside, above and below, in the depth, and that is hard to nail down because, at some point, it participates in a phantastical sequence.[226]

And I looked at the mirror. I still remember because my head was still big. I was thin, I had no breasts, and I was sick. […] I asked myself as Nontyatyambo, 'Do you want to die or do you want to live?' Something told me, 'I want to live.'[227]

- Nontyatyambo

In the second chapter, I claim that the *Through Positive Eyes* arts initiative contributes to the public shift in representation and the private de-stigmatisation of people living with HIV in South Africa through the medium of photography. Inspired by the participants' narratives and images, I found the concept of the 'mirror' repeatedly emerging as an experience that fostered an individual's sense of acceptance. In this chapter, I develop this concept of 'the mirror' in order to argue that individuals living with HIV/AIDS can gain insight into themselves through self-reflection in the mirror and also through reflection in their photographs. I will look closely at two of the self-portraits to support my argument –Nontyatyambo and Lindiwe. With the emphasis on *living*, sometimes just *surviving*, within these self-portraits, the 'mirror' – physical and mental – embodied a meaningful space of reflection.

Several post-colonial theorists have invoked a deep meaning behind the concept of the 'mirror', particularly the 'African mirror'.[228] In the work of Achille Mbembe, the concept of the mirror is used as a metaphor to explore how 'Africa' and 'Africans' have been subject to the colonial gaze and have internalised this inferiority physically and mentally. As he writes in *On the*

[226] Mbembe, Achille. *On the Postcolony*. Berkeley: University of California Press, 2001. 241.
[227] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2.
[228] See Achille Mbembe (2001) *On the Postcolony*, Ngũgĩ wa Thiong'o (1998) "Oral Power and Europhone Glory: Orature, Literature, and Stolen Legacies." *Penpoints, Gunpoints and dreams: Toward a Critical Theory of the Arts and the State of Africa* and Franz Fanon (1952) *Black Skin, White Masks*

Postcolony, Mbembe describes the mirrored 'heart of darkness'[229] held up to Africa at the end of the 20th century:

> This is the kind of mirror held up before the continent at the end of the frenzied century. What do we see in it? A brief and dissipated life in every sense. Men and women who pass by and change, forms, languages, animal figures deprived of sound. The spectacle of a world marked by unbridled license. The power of the negative and the sweet poison of corruption. A vast scaffolding of dead elements. Obscure memories of what used to exist. Mummies lying broken on the earth. Cadaverous statues and idols, whose souls have fled the form and, vanquished and driven to the edge of reality, to the sinister frontiers of the world, suddenly begin to stutter and dance on the public square, filling the living with terror. The comedy of a self that chews itself up, along with anything it gets between its jaws. A world that remains transfixed before the inexplicable, and that flies apart with large and small explosions, unveiling, as it does, the excess of an age that exults, so to speak, in suffering, festivity, and drunkenness mixed together."[230]

As Mbembe demonstrates here, the 'African mirror' has long been pieced together by critical shards of glass, mostly reflecting the continent's devastations. With the rapid spread of HIV/AIDS across the continent at the end of the 20th century, the West was granted yet another raison d'etre/justification to perpetuate the downtrodden 'African mirror'. Ngũgĩ wa Thiong'o's discussion of the 'colonised mind' and the 'cultural annihilation' subjected to Africans also confronts the fate of the African reflection: "Africa has had such a fate in the world that the very adjective *African* can call up hideous fears of rejection."[231] This rejection, or marginalization, further encumbers one's self-construction as an HIV-positive individual, and falls prey to the persistent stigma that has infiltrated not only African, but for my study's purposes specifically, South African society. As the marginalisation of being a black African combines with the marginalisation of being a person living with HIV, the internalised stigma of mind and body comprises one's self-reflection and sense, or lack thereof, of self-worth. In addition to the taboo of the sexually transmitted virus, there continue to be images circulating that link HIV with suffering

[229] This reference is significant in my own trajectory as Joseph Conrad's *Heart of Darkness* was my first introduction to the Western perception of Africa, yet my first exposure to the work being contextualized and problematized was only once I went to study Cultural Studies and African Studies at UCLA.
[230] Mbembe, Achille. *On the Postcolony*. Berkeley: University of California Press, 2001. 239.
[231] Wa Thiong'o, Ngũgĩ. "The Language of African Literature." *Decolonising the Mind: The Politics of African Literature*. Oxford: James Currey, 1986. 29.

and death, contributing to the overwhelming stigmatization of the 'HIV mirror' in Africa for those infected and affected by the virus:

> Africa has been effectively demonized in a post-colonial discourse of perpetual catastrophe and unnatural disasters. This undifferentiated apocalyptic Africa has proved an ideal site in which to find and 'see' disease. 'African AIDS' thus condenses ancient fears concerning contagious disease, together with vengeful fantasies concerning 'excessive' sexuality, understood in essentially pre-modern times as both the source and the cause of AIDS.[232]

Considering that Watney wrote this in 1989, nearing the end of the first decade of the AIDS epidemic, these representations of Africa and people living with HIV/AIDS in Africa have been shifting towards a new imaginary. The individuals participating in the *Through Positive Eyes South Africa* initiative confront the falsity of the fearful and phantasmal as they portray their own trajectories through narrative and photographs in the hope to represent HIV/AIDS in Africa in a new light.

This evokes how socially constructed notions often determine the way an individual perceives himself and, as Goffman describes, that it is the society that generates the marking of the stigmatised individual, which usually turns to shame.

> Shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing.[233]

As he speaks of this conjured shame, Goffman references a narrative of someone's experience looking into a mirror – thereby confirming the significance of self-reflection on internalised stigma. In South Africa, the 'mirror' was further fractured by the nation's traumatic history of HIV/AIDS and its denialism. Yet despite the nation's polarized past, South Africans have made progress through demanding education and treatment access and availability. Just this year, in August 2011, Deputy President Kgalema Motlanthle announced that "all people with HIV with CD4 counts below

[232] Watney, Simon. "Mission Positions: AIDS, 'Africa,' and race." *Selection of Essays*. Durham: Duke University Press, 1994. 118. [Essay originally published in 1989.]
[233] Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963. 18.

350 cells/mm^3 will be offered [access to] antiretroviral treatment,"[234] to implement the World Health Organisation's most recent protocol of treatment guidelines for earlier ART initiation. With advancements like this, the 'HIV mirror' is in a position to change and it is in the hands of South Africans to create a new reflection in the 'mirror'. As I have argued, *Through Positive Eyes South Africa* placed cameras into the hands of South Africans living with HIV/AIDS in order to adjust the lens and generate new reflections. Therefore, I consider the recurring images of the 'mirror' and the metaphor of the photograph as 'mirror' to analyse how these private, internal reflections affect public perception.

[234] "ARVS Open To All: Motlanthle." *Sunday Times Live*. 12 August 2011. Web. Available: http://www.timeslive.co.za/local/2011/08/12/arvs-open-to-all-motlanthe. [1 February 2012].

Figure 46: *Nontyatyambo's Self-Portrait*[235]

[235] Nontyatyambo. *Nontyatyambo's Self-Portrait*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

I Want To Live: Mirror Projections and Voice Lessons

The self-portrait of Nontyatyambo[236] highlights the impact of a projection in the mirror not only as the 'mirror' is utilized as a measure for her physical appearance, but also as an indicator for her mental frame. Nontya is the first to lead our group sessions into song or dance as she revealed the artist within her activist self right from the start of the process. Nontya exudes a certain aura of self-confidence that is probably linked to the fact that she is blessed with an extremely supportive family. From the moment she learned of her diagnosis, she chose to disclose to her family and be open about her status. Having heard so many stories relaying the antagonistic response of many families on hearing of the HIV-positive diagnosis of a family member, it is not yet the norm where families are so immediately supportive when they learn about a positive diagnosis of a family member. While Nontya was fortunate to have the support of her family, she still experienced stigma by others:

> What I've done during the time I was struggling to accept my HIV status because people were pressurizing me. People were talking, and it was difficult for me, you know? Even to go outside because – to face people because they were talking.[237]

Many open HIV-positive individuals, particularly when they physically appear sick, face the current of stigma that still exists in South Africa; and it is individuals like Nontya who, through her images, will contribute to changing the flow of stigma. As I explored this notion in my discussion of Betty in the second chapter, I re-emphasize that it is crucial to distinguish the individual living with HIV from the pre-existing discourse surrounding the virus. This truth opens up the reality that the 'mirror of HIV' needs to be transformed, and the process, which *TPE* participants experience is one strategy through which the mirror can evolve. The proactive experience of internal reflection

[236] Age 29, Living with HIV for 6 years, 832 Photographs
[237] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2.

through prose and image leads to the individual's external resistance to identification as *being* the virus rather than *living with* the virus.[238]

When Nontya was initially diagnosed, she was the image of the "wasting 'African AIDS body' fit[ting] neatly into the pre-existing Western image of a wasting continent peopled by victim-bodies of illness, poverty, famine."[239] But Nontya did not let her CD4 count of 0.8 and her weight of 28 kg hinder her hope to inspire others; her story visibly demonstrates the efficacy of being on anti-retroviral therapy (ART). While Watney writes in the late 1980's of the "two guises" under which AIDS is seen – the medical retrovirus that inserts itself into human DNA to transform and replicate itself and the human bodies it "strips of sensual luxury," the "cultural agenda of AIDS" that he speaks still exists but is on its way to being transformed. The 'forbidden further enquiry' is in the midst of human interrogation, and this is what *TPE* sets out to cultivate. After relaying a dream she had of herself "talking in front of so many people – in one of the stadiums in [her] area of Tsakane,"[240] Nontya carries us into her 'moment in the mirror' – a pivotal moment of agency that would determine the trajectory of both her virus and her life.

> And I looked at the mirror. I- I still remember because my- my- my- my head was still big. I was thin. I had no breasts. And I was – I was sick. But I was taking medication. I – I just looked in the mirror. I asked myself as Nontytyambo that, 'Do you want to die or do you want to live?' And something told me like, 'I want to live'. I want to live.[241]

As Nontya speaks of her self-reflection in the mirror, her face changes from bright to brighter as if her will to live was re-boosted once again right in this space as we spoke. In this way, Nontya's description of seeing herself in the mirror is central to her decision to live positively with HIV. But psychologically, what happens during this reflection of oneself in the mirror?

Psychoanalytic theorist Jacques Lacan developed a theory from his work in child psychology and social theory called "the Mirror Stage." This "Mirror Stage" is fundamentally the

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[238] See Simon Watney's "The Subject of AIDS" (1987) and Gill Green and Elisa Sobo's *The Endangered Self: Managing the Social Risks of HIV*. (2000).
[239] Patton, Cindy. *Inventing AIDS*. New York and London: Routledge, 1990. 83.
[240] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2.
[241] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2.

stage where the infant, who thus far is only cognizant of himself in relation to his mother, or caregiver, finds his own reflection in the mirror and subsequently achieves his initial identification of himself as an independent being.[242] It is through this identification in the mirror that Lacan argues the baby becomes aware of his status as a "Self".[243] While Lacan's theory was derived from an infant's subjective identification in a mirror, the theory extends itself to apply to any individual who identifies with an image of himself outside of himself:

> We have only to understand the mirror stage *as an identification*, in the full sense that analysis gives to the term: namely, the transformation that takes place in the subject when he assumes an image.[244]

It is in her disclosure of this moment that Nontya transcends the physical mirror to engage with the internal mirror; the physical reflection triggers the internal self-assessment. Quite fascinatingly, in a book on Lacan, the writers define this register of identification as "an organizing principle of development [where] if I have identified with an image outside myself, I can do things I could not do before."[245] It is also suggested that the identification in the mirror enables one to piece together in one image what may be felt as fragmented for the person. For example, an individual who has just been diagnosed with HIV, like Nontya, sees her physical body looking one way but is emotionally compelled in a different direction. Thus, she has the chance to see herself in a complete form when looking in 'the mirror', even if it is an "imaginary wholeness."[246]

> The *mirror stage* is a drama whose internal thrust is precipitated from insufficiency to anticipation – and which manufactures for the subject, caught up in the lure of spatial

[242] Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]
[243] Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]
[244] Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]
[245] Leader, Darian and Groves, Judy. *Introducing Lacan*. Ed. Richard Appignanesi. Cambridge: Icon Books, 2000. . [Originally published in 1996.]
[246] "Mirror stage." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Mirror_stage. [13 October 2010.]. 2.

> identification, the succession of phantasies that extends from a fragmented body-image to a form of its totality.[247]

On the one hand, it is apparent how Lacan's theory recognizes the many components of the individual and this particular process of self-recognition and self-identification but on the other hand, Lacan's later works also recognize the significance of how the outside world lends itself to constructing identity. Interestingly, Lacan clearly states in his essay on the 'Mirror Phase' that "the *I* is symbolized in dreams by a fortress, or a stadium – its inner arena and enclosure…dividing it into two opposed fields of contest where the subject flounders in quest of the lofty, remote inner castle..."[248] Through my own interpretation of Nontya's dream, I read it as a reflection of her own desire to speak to herself, and the stadium dream created that open door for her to engage with her own emotions. As Nontya recalled this moment during the interview, she looked away as she pondered the moment that altered the course of her life, and then she looked directly at me as she forcefully said, and then repeated the words, 'I want to live.' Anthropologist Veena Das describes this decisive moment through the relationship of the physical body to language articulation when she describes,

> …the transactions between body and language lead to an articulation of the worlds in which the strangeness of the world revealed by death, by its non-inhabitability, can be transformed into a world in which one can dwell again, in full awareness of a life that has lived in loss. This is one path towards healing – women call such healing simply the power to endure.[249]

Nontya's physical appearance and her internal mental and emotional articulation represent her shift from the realm of death to the realm of life as she reflects on her own image in the 'mirror' of her dream. While Nontya is looking at herself in the mirror, there is a larger social construction also at play in her mirror reflection. It is not only regarding her own reflection but the images carry the

[247] Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]
[248] Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]
[249] Das, Veena. "Language and Body: Transactions in the Construction of Pain." Kleiman, Arthue, Veena Das, and Margaret Lock. Eds. *Social Suffering*. Berkeley: University of California Press, 1997. 68.

weight of all the reflections encountered during public display. Ngũgĩ wa Thiong'o explains that how we perceive ourselves is generally based on socially constructed images which lend to our own misperceptions.

> Our whole conception of ourselves as a people, individually and collectively, is based on those pictures and images which may or may not correctly correspond to the actual reality of the struggles with nature and nurture which produced them in the first place. But our capacity to confront the world creatively is dependent on how those images correspond or not to that reality, how they distort or clarify the reality of our struggles."[250]

But, as Ngũgĩ also says, it is up to the individual and the collective to confront these false images and restore the images of reality to the social and cultural register. With the responsibility of creating one's own self-portrait for oneself, it also creates the opportunity to establish a new image for others to witness – in this case, a new image of living with HIV/AIDS. Steve Biko reinforces the necessity to resist the legacy upheld by South African political history by reclaiming one's identity and one's self-awareness:

> Further implications of B.C. are to do with correcting false images of ourselves in terms of Culture, Education, Religion, Economics. The importance of this also must not be understated. There is always an interplay between the history of a people i.e. the past, and their faith in themselves and hopes for their future. We are aware of the terrible role played by our education and religion in creating amongst us a false understanding of ourselves. We must therefore work out schemes not only to correct this, but further to be our own authorities rather than wait to be interpreted by others."[251]

Like Steve Biko, *Through Positive Eyes* also seeks to engage with and contribute to a paradigmatic transformation, thus providing the opportunity to acknowledge publically the denied, stigmatised past of HIV/AIDS in South Africa through the creation of new images to substantiate this redemption of "Self".

In his keynote lecture delivered at the Drama for Life Festival, held in August 2010 at the University of Witswatersrand, David Gere referred to the significance of Lacan and the altered paradigm to which the theory of 'the Mirror stage' contributes. Gere spoke of the encounter both with oneself and the ensuing encounter by others with the person living with HIV/AIDS, rendering

[250] Wa Thiong'o, Ngũgĩ. "The Language of African Literature." *Decolonising the Mind: The Politics of African Literature*. Oxford: James Currey, 1986. 15.
[251] Biko, Steve. "The Definition of Black Consciousness." *I write what I like*. Northlands: Picador Africa, 2004. (Originally published 1978). 57.

the experience knowable to others and enabling further de-stigmatisation.[252] In the following section I will analyse a series of Nontya's photographs as a reflection of her moment in the mirror and the essence of what she aims to inspire in herself and in others – "RESPECT." Having previously discussed the significance of the HIV-Positive T-shirts, what one wears is its own channel of representation and in this series, it weighs in on her images. As Nontyatyambo respects herself in the mirror and through her own camera lens, the audience is privy to see where her decision 'to live' has brought her.

Figure 47: *Respect Series*[253]

Nontya has become the speaker in her dream, and as she continues on her journey towards self-acceptance, her own construction of self emphasizes living life after an HIV-positive diagnosis. Nontya is the kind of woman that does not just demand respect but she earns it in the way she commands a room with her energy and sharp wit. In Nontya's case, it is particularly apt as she is

[252] Gere, David. "Drama for Life Festival Keynote." University of Witswatrsrand. August 2011. Lecture.
[253] Nontyatyambo. *Respect Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

not only open about her status, but she is also open about her family life with her HIV-negative partner and the children they are raising together.

> What I've realized as a young woman who is living with HIV is that irrespective of whatever chronic illness that you are living with, it does give some boundaries in your sexual life be it in your relationship or in your friendship. I'm in a relationship now and my partner is HIV-negative. And we are happy because every time if someone is approaching me… what I will tell that person is that I am living with HIV, the first thing that I do. I've got this little friend, which is in my blood. You take me or you leave me. Fortunately, my partner is very, very supportive to me and definitely, we are so happy.[254]

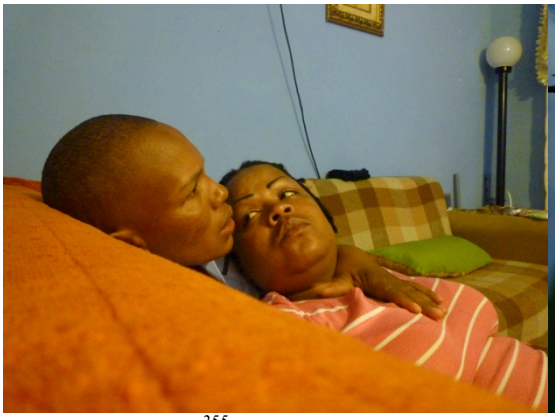

Figure 48: *In Love*[255]

Figure 49: *Playing Outside*[256]

The majority of Nontya's photographs are of self-portraits, images of herself with her partner, and of their children. While Nontya discusses how all relationships are challenging, the challenge of being a serodiscordant couple is further complicated by the challenge of living as an, 'out' lesbian couple in South Africa. There are two contributing factors to this challenge. Gabriele Griffin speaks of how "many lesbians [feel] themselves to be invisibilised by the foregrounding of HIV/AIDS as the main agenda item in the fight for lesbian and gay rights,"[257] but Nontya withstands this challenge as she balances her chosen roles as an HIV/AIDS activist and as a lesbian and gay rights activist with resilience. The other significant challenge is the pervading seriousness

[254] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 3.
[255] Nontyatyambo. *In Love*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[256] Nontyatyambo. *Playing Outside*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[257] Griffin, Gabriele. "Introduction." *Representations of HIV/AIDS: visibility blue/s*. Manchester: Manchester University Press, 2000. 3.

of violence against lesbians.[258] Even with its lengthy human rights accord in the new South Africa Constitution, lesbians fear for their lives on a daily basis in South Africa where gender-based sexual violence is widespread. Although the government is taking steps toward furthering gender and sexual equality and protective measurements, this is another 'social pariah' that needs its own in-depth analysis.[259] But Nontyatyambo does not allow the space for these 'obstacles' to get in her way or to keep her down; she is constantly moving forward, determined to make a difference. Although she does not mask the pain and hurt she has experienced on her journey, Nontyatyambo draws focus to the uplifting aspects in her life, especially the youngest child she shares with her partner with whom she has a special connection – particularly their love for nature and animals. This bond is represented by one of her two signature photographs:

Figure 50: *Flying Birds*[260]

[258] One of many acts of violence against lesbians was the 2006 murder by stoning and stabbing of 19-year old lesbian. This case of Zoliswa Nkonyana has been all over the media as her murders were finally convicted in February 2012 with sentences of 18 years each. Many wanted them to get the death penalty. See *Cape Times* article from 1 February 2012. http://www.sundaytribune.co.za/lesbian-murder-sentence-a-message-1.1225367.

[259] See the Lesbian and Gay Equality Project, http://www.equality.org.za, Coalition of African Lesbians, http://www.cal.org.za, or other recent articles like http://www.informafrica.com/breaking-news-africa/mounting-violence-haunts-south-africa's-gays-and-mobilizes-activists/.

[260] Nontyatyambo. *Flying Birds*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Here, Nontya captures a stirring photograph of birds flying over homes near where she stays. Birds have many symbolic meanings – a few of which tie in clearly to Nontya's portrayal of herself. Firstly, birds have access to the earth and the sky, thereby bridging the physical earth with the spiritual heavens another link to my interpretation of Nontya's dream when she decides to choose life over death. Birds can also symbolize freedom – this freedom can reflect Nontya's freedom to be public with her HIV-positive status and with being a lesbian in spite of the serious danger involved especially with the latter identity in today's South Africa. In another interpretation, female birds are free and yet they are tied down to nests when they have offspring – in a way the freedom of the birds can be read as a symbol of Nontya's empowered self-confidence while the nesting can relate to her overall concern for her family. When she addresses herself to say 'Nontyatyambo, just go out there and show them that you can do this,' it is evident that this moment initiated her healing:

> Who do you live for? I live for myself not for other people. Let me just forget what people say. Let me forget what my friends are saying. Let me just start taking it up to me now – the realizing that there is life after HIV. […] Anyway, 'Nontyatyambo, just go out there and show them that you can do this.' It's whereby I feel like it's the day I started to do something about the virus that I have – accepting my status. And which is the first healing for me because you can even take medication but if you don't accept your HIV status, you are not going anywhere. The first thing that I've done was to accept my HIV status as a person. And then took a treatment, my antiretrovirals as a bonus. And then I went out there. [….] Let me be the voice even to those people who are voiceless.[261]

How would Gayatri Spivak speak to this scenario where the 'subaltern,' 'marginalised' black African HIV-positive woman wants to be the 'voice' for the 'voiceless?' Who is considered the 'voiceless' in this image? Who is the 'Other' now? *TPE* does not support the notion of 'giving voice' but of creating a space for that voice to be used and to be heard – through language and imagery, prose and photographs. No individual has the power to 'give voice,' but everyone has the power to listen. Although Nontya's agency as a 'black, marginalised, African, HIV-positive woman' is impeded by society, Nontya does not allow herself to be defined by what other people say or by how she is categorised; she drives her own identity.

[261] Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2-3.

Some arts-based initiatives involve story-telling of the past up through to the point of diagnosis so that someone can be memorialized and remembered like The Memory Box Project, but *TPE* enters in the middle of the post-diagnosis journey to emphasize the present-day experience. While I will interrogate the efficacy of whether the *TPE* initiative also "enables [its participants] to reclaim their own bodies from under the 'gaze'," the project fosters the process for HIV-positive individuals like Nontya to no longer be framed by the lens of an outsider but to interpret their own experiences and reclaim their bodies as their own. Nontya's self-confidence lends itself to her interest in giving advice to others, demonstrating her desire to challenge others to jumpstart their own healing towards self-acceptance. Harriet Deacon speaks to this effect as she anticipates the possibility for the transformation of stigmatizing representations:

> …in certain conditions stigmatized people may contest and even transform stigmatizing representations and practices – and that a social psychology of stigma needs to take account of human capacity for agency, and to allow for the possibility of resistance and change. […] Stigmatised identities might even become a platform for group mobilization and resistance.[262]

And here only five years later, its is self-evident how this initiative enables exactly this - *Through Positive Eyes* is that 'platform for group mobilization and resistance' as the narratives and photographs will ultimately be taken to the United Nations as a lobbying and advocacy effort for increased access and greater affordability for antiretroviral treatment globally. While Nontyatyambo shares her experience of how physically seeing her body in the mirror contributes to her own turning point of acceptance and self-healing, it is also revealed in some of the self-portraits how individuals look inside themselves through the photographs they capture of inanimate objects or nature.

[262] Deacon, Harriet. "Unravelling the Contexts of Stigma: From Internalisation to Resistance to Change." *Journal of Community and Applied Social Psychology* 16.6 (2006): 411-417.

Figure 51: *Lindiwe's Self Portrait*[263]

[263] Lindiwe. *Lindiwe's Self-Portrait*. March 2010. *Through Positive Eyes*. UCLA Art|Global Health Center.

It's Not Like I'm Sick in the Hands: A 'Marked' Woman Changing the Community Mirror

> As the face of AIDS becomes transfigured… so will our response as a society.[264]
> - Monroe Price, Communications Scholar

Lindiwe[265] is a thirty-seven year old single mother of four children, and proud coordinator of her community's cooking group, responsible for the food of all the community's events like weddings, birthday celebrations, and funerals. Her role in this group is significant because she was excluded from participating after revealing her diagnosis. The 'mirror' image reflected by her community was that of a 'marked' woman,[266] no longer visible for who she was but for the virus that she lived with. It seems that her community, in an attempt to alleviate its own 'suffering,' marked HIV/AIDS, and therefore Lindiwe, as their scapegoat.

Ironically, it was the pain of this stigma that compelled Lindiwe to become the catalyst for change of her own community 'mirror'. After having lived in secrecy with her status for seven years, she reveals through her narrative and photographs how her journey brought her from a place of coping with shame to finding dignity in her own way:

> The whole family knows about my status. My community knows about my status. And I'm prepared to go to a national TV to talk about it. I'm not scared. And I believe that after HIV, there is still life. It depends how you want to live your life.[267]

While it is apparent Lindiwe has achieved a certain level of acceptance, she does not ignore the challenge she faced with disclosure and the pain involved in a positive HIV diagnosis. In her reflection of these realities, she captures images reminiscent of the images taken by Gugu as discussed in Chapter One – images of rubbish – symbolic of the way she felt in the eyes of others and to herself. In order to witness the shattering of the mirror, one must first witness what is first reflected back.

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[264] Price, Monroe E. *Shattered Mirrors: Our Search for Identity and Community in the AIDS Era*. Cambridge: Harvard University Press, 1989. 3.
[265] Age 37, Living with HIV for 12 years, 920 Photographs
[266] See Gabrielle Griffin's *Representations of HIV/AIDS: visibility blue/s (2000)* and Peggy Phelan's *Unmarked: the politics of performance (*1993)
[267] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 1.

Figure 52: *Dumped Series*[268]

> It was like when I was diagnosed I felt that I was dirty, outside inside.
> So I felt like that rubbish. When you look at that rubbish, it tells a story whereby you don't feel like you are welcome any more in the world.
> It's like you can be dumped anywhere, anytime.[269]

These photographs of the red and white truck cabs rusting away, the bus deserted in the middle of a field, and the scattered rubbish of plastic, paper and tins, all seemingly just 'dumped anywhere, anytime,' validate how Lindiwe expresses her moments of dispirited self-reflection in her images. As with Gugu, Lindiwe's association with herself feeling like 'rubbish' is one of the many effects of Ngũgĩ wa Thiongo's 'cultural bomb' discussed earlier. When oppression, subjugation, inferiority are all inflicted on a people generation after generation, it is inevitable for the individual

[268] Lindiwe. *Dumped Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[269] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 1.

and the community to continue to feel oppressed, subjugated, inferior. In this instance, photography is the vehicle through which these sentiments are represented.

> Photographs really are experience captured, and the camera is the ideal arm of consciousness in its acquisitive mood. To photograph is to appropriate the thing photographed. It means putting oneself into a certain relation to the world that feels like knowledge – and, therefore, like power.[270]

Indeed, Lindiwe appropriates these images to express her own sentiments to demonstrate her relationship to the community around her. A photograph is not just an image captured of that time and place, but it is the nexus of all the influences and environs that lead that individual to take that particular photograph at that time. In South Africa, the political, social, cultural and historical contexts all contribute to this sense of a lack of self-worth, which Ngũgĩ wa Thiong'o recognizes and deplores.

> How we see a thing – even with our eyes – is very much dependent on where we stand in relationship to it. […] …how we view ourselves, our environment even, is very much dependent on where we stand in relationship to imperialism in its colonial and neocolonial stages; that if we are to do anything about our individual and collective being today, then we have to coldly and consciously look at what imperialism has been doing to us and to our view of ourselves in the universe.[271]

While Lindiwe captured the way she saw her relationship to these symbols of 'rubbish', essentialising her struggle within, the majority of her photographs symbolized her breakthrough to transcend the virus barrier and connect with people. From feeling like rubbish to making a difference as a support group leader, Lindiwe's process of re-establishing her sense of self-worth reveals itself through her photos of hands. Even from the first time she mentioned hands in a conversation with her grandmother who assumes a helplessness in Lindiwe, it is evident how capability plays a role in her journey towards acceptance:

> 'No Granny I will do anything for me. It's not like (slight chuckle) I'm sick in the hands. It's just that I'm living with the virus.'[272]

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[270] Sontag, Susan. *On Photography*. London: Penguin Books, 2008. 3.
[271] wa Thiong'o, Ngũgĩ. "The Quest for Relevance." *Decolonising the Mind: The Politics of Language in African Literature*. Oxford: James Currey, 1986. 88.
[272] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 2.

Lindiwe disassociates her virus from her hands – 'it's not like I'm sick in the hands' – as she sardonically chuckles over her grandmother's eagerness to help. Her reflection on the capability of her own two hands and the power of others' hands joining together encourages the process of confronting the social mirror. As part of the cooking group, Lindiwe used her hands for everything so when she was shunned from the group, it was because of the association with her hands and transmission. It is from this point that Lindiwe's hands became her symbol of survival during the *TPE* process – and it is this survival, this emphasis of living with HIV, that needs to be mirrored on an individual and on a social level in South Africa and beyond on the continent.

> Anything that you are doing, you are doing it with hands. You touch people with hands. You greet people with hands. You hug a person with hands. So that hands shows that we love people.[273]

[273] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 6.

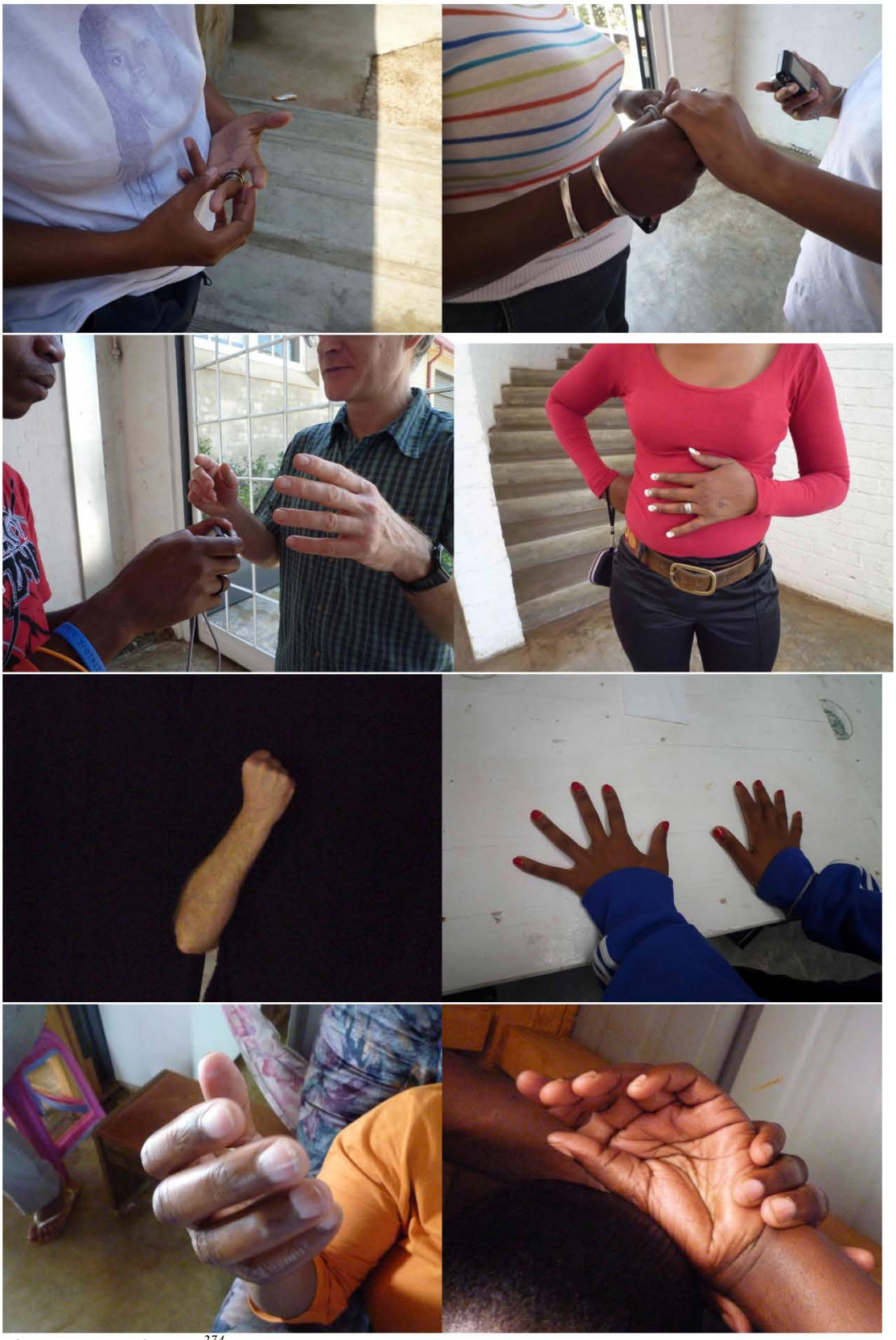

Figure 53: *Hand Series*[274]

In a closer analysis of these photos, it is clear that the faces in the photos are either non-existent or partially obscured, thereby confirming the irrelevance of the 'who' and focusing on the hands

[274] Lindiwe. *Hand Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

themselves as containing the emotional mirror. From holding another's hand to using hands to explain, from touching oneself with one's own hand to accepting or asking with a hand, the hand is the mirror reflection.

After being shunned from her community cooking group, Lindiwe sought ways in which she could assure other women that 'after HIV, there is still life.' She created a space where women living in fear of disclosure and the consequential stigma are given a chance to be 'free to each other,' and she shares these women with us through their hands.

Figure 54: *Open Hands for Freedom*[275]

Figure 55: *Closed Hands for Strength*[276]

> For the open hands (showing open hands), it's whereby we we accepted our status. And show the world that we are ready to move on with our status. […] It's like anything that we are doing with- when opening your hands, it shows that you are free.
> […]
> And the closed hands (showing closed fist) is for that we won't let anything to slip in our hands. We- we will hold anything that will- will be a light to us. We will hold it with our bones. And we will grab anything that will help us in the future.
> […]
> It's that we grip any chances that we can get so that we can get help. So that we can be a people who can be recognized in the future. We want to show the world that we are ready now. That's why we're closing the hands so that any opportunity that we might find, we need to grip with our hands and move on.[277]

It is through her hands and the hands of others that Lindiwe overcame her personal stigma and was able to encourage her community to overcome their stigma. She was accepted eventually by the

[275] Lindiwe. *Open Hands for Freedom*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[276] Lindiwe. *Closed Hands for Strength*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.
[277] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 6.

cooking group , thereby making her person mark on the shift in representation of the social mirror of HIV/AIDS in South Africa:

> And they don't have this discrimination of- or stigmatization of you know, 'This one is living with HIV' any more. There's other women in the club who are positive. It's not only me. […] Everything has changed actually. They are supportive. They are very supportive. And we love each other. We love each other. [278]

The transformation from not being allowed to be a part of the community cooking group to being one of the lead cooks is an example of how Lindiwe's hands reflect her own journey of self-acceptance and acceptance by others. Lindiwe's hands are the mirror in her narrative and images, and it is in this closer analysis of her self-portrait that it is evident how the hands of her support group, the hands of her cooking group, and her hands themselves have all contributed to her process of destigmatisation.

Although I approach the change in power dynamic in the *TPE* process where the 'representer' is the 'represented,' the essence of *TPE* is that the self-portraits do not distinguish themselves as 'true' images in protest of 'false' images, or of 'living' images as opposed to 'dying' images, but candidly encompass the complex realities of living with HIV/AIDS in South Africa in 2010. Having looked more closely at some of these self-portraits, it is apparent how *Through Positive Eyes South Africa* contributes to changing the lens of internalised stigma by engaging with the 'mirror's' failure to account for *'time as lived.'*[279] The internalised stigma that bares itself within a person living with HIV/AIDS does not just exist inherently – it is generated by the social constructions of prejudice, often so deeply embedded within a society that it can appear impossible to overcome. But as is evident even in the select self-portraits, it is possible to shatter and then reconstruct the mirror – both the individual and the social mirror, thereby contributing to the paradigm shift in how people living with HIV/AIDS see themselves and are perceived by others.

[278] Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010. 5.
[279] Mbembe, Achille. *On the Postcolony*. Berkeley: University of California Press, 2001. 8.

CONCLUSION:
THE LENS OF STIGMA IS CHANGING…

The HIV/AIDS pandemic is so widespread and has *infected* and *affected* so many individuals that its related activism has thus far spanned three decades. Art has played a significant role in HIV/AIDS activism, and the *Through Positive Eyes* arts initiative is one of many projects striving to bridge an individual therapeutic process with the public recognition of living testimony on display. In looking at art's strength, the following quote by Douglas Crimp was used as an introduction to David Gere's course, "Make Art/Stop AIDS":

> …art does have the power to save lives, and it is this very power that must be recognized, fostered and supported in every way possible. But if we are to do this, we will abandon the idealist conception of art. We don't need a cultural renaissance; we need cultural practices actively participating in the struggle against AIDS. We don't need to transcend the epidemic; we need to end it.[280]

There are many arts-based projects working towards shifting the representation of people living with HIV/AIDS in the current paradigm. Projects like the Bambanani Women's Group Memory Box Project and Longlife Project[281], the Beyond Awareness Mural Project[282] and Siyazima Beads Project[283] have all sought to alter the dominant lens of stigma around HIV/AIDS in South Africa using a variety of arts-based strategies like the creation of memory boxes, body maps, community-based murals, and beaded ribbons and figures. But the *Through Positive Eyes* arts initiative is unique in its process of fusing visual photography with narrative prose as a vehicle for self-documentation and new representation.

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[280] Crimp, Douglas. "AIDS: Cultural Analysis/Cultural Activism." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge, Mass.: MIT Press, 1988. 7.
[281] "The Memory Box: Background History of the Bambanani Women's Group." Bambani Women's Group. [Online] Available: http://www.memorybox.co.za/index.php?option=com_content&task=view&id=12&Itemid=53. [1 February 2012].
[282] "Beyond Awareness Campaign: AIDS Mural Project." South Africa Department of Health, HIV/AIDS and STD Directorate, 199?. [1 February 2012]. or See http://www.popline.org/ics-wpd/mmc/media/plsoa233.pdf. BY HIV/AIDS and STD Directorate, Department of Health.
[283] Wells, Kate, Edgard Sienaert, and Joan Conolly. "The *Siyazima* Project: A Traditional Beadwork and AIDS Intervention Program." Cambridge: Massachusettes Institute of Technology, 2004. Vol. 20. No. 2. Spring 2004.

Stigma is a challenge globally for people living with HIV/AIDS; these individuals face prejudice on the part of others as well as internal shame. Being one of the facilitators and following my close analysis of the *TPE* process, in this thesis I have argued that the *Through Positive Eyes* arts initiative with its focus on transformative photography as a tool, or strategy, contributes to changing the lens of stigma of South Africans living with HIV/AIDS. But it is also important that as I conclude, I raise some of my unresolved questions that could be beneficial for future arts-based initiatives to consider when exploring the complexities of stigma around HIV/AIDS.

Effectively combating stigma on a larger scale is far more complex than it first seems – as private and public stigma are inherently intertwined, both must be challenged simultaneously in order to be effective. In my analysis of several self-portraits drawn from the *TPE* project in this thesis, I focused on the internalised, private processes of de-stigmatisation and self-reflection and the therapeutic effect on both through photography. Another point of analysis could be an evaluation, if possible, of the spectator's encounter with the self-portraits on display. Commenting on the role of the witness, Douglas Crimp writes, "For AIDS activist artists, rethinking the identity and role of the artist also entails new considerations of audience."[284] This may be difficult to survey but it would certainly be beneficial to gauge the impact on combating stigma – and of whom? Who are the people going to see these self-portraits? How are they "seeing" the images? And how are their preconceptions being challenged or substantiated? How can a project like this engage observers who otherwise may not be interested? As the self-portraits reveal de-stigmatisation of the mind and body and identification of self-worth through 'mirror' reflection and reflection in one's photographs are realised through the utilisation of a new visual vocabulary to reach for a new HIV/AIDS imaginary. In Mexico City and Rio de Janeiro, these efforts have begun through a collaborative effort with the local partners; in South Africa, expansion and dissemination of the self-portraits is taking longer to materialise, but as soon as these efforts get re-energised, efforts towards getting these self-portraits out in the public realm will continue.

[284] Crimp, Douglas with Adam Rolston. *AIDS Demographics*. Seattle: Bay Press, 1990. 19.

Another poignant concern to consider for future initiatives, and also for my own inquiry should I do further research on *Through Positive Eyes,* is to look at the significance of native language. In the first two *TPE* initiatives*,* the participants in Mexico City relied on Spanish and in Rio de Janeiro, Portuguese was spoken for the photography workshop and the interviews. But in Johannesburg, it was decided to use English as the primary language of communication. Indeed there were a range of native languages among the group, and it was debated briefly, particularly in relation to one of the participants, but ultimately everything was done in English. Ngũgĩ and Steve Biko both interrogate the consumption of language on the African continent and the necessity for emphasising the use of traditional languages, spoken and written.[285] While Biko ses the role of language in the "development of an inferiority complex,"[286] Ngugi writes, "The choice of language and the use to which language is put is central to a people's definition of themselves in relation to their natural and social environment, indeed in relation to the entire universe."[287] Why was it decided to work solely in English in South Africa and why only in this country while participants in other places spoke in their mother-tongues? On the other hand, in considering the other two countries, what did it mean for the participants to be translated not only in language but cross-culturally, and how does this alter the representation affected by the participants, if at all? This language debate also lends itself to the complexities of visibility and invisibility, what is being revealed and what is being concealed to one's self but especially during the visual encounter with the observer. The question of language also has a strong association with the concepts of empowerment and agency, which I do consider throughout my thesis but not in the context of language.

Overall, the messages revealed in the *TPE* photo narratives present the daily challenges and complexities of living with HIV/AIDS in South Africa but they also exude a sense of hope and

[285] See Ngũgĩ wa Thiong'o *Decolonising the Mind: The Politics of Language in African Literature* (1986) and Steve Biko's *I Write What I Like* (1978).
[286] Biko, Steve. "Whhat is Black Consciosuness?" *I Write What I Like*. Northlands: Picador Africa, 2004. 118-119. [Originally published 1978)
[287] wa Thiong'o, Ngugi. "The Language of African Literature." *Decolonising the Mind: The Politics of Language in African Literature*. Oxford: James Currey, 1986. 4.

optimism for the future in spite of these. While the group strongly queried the government's ability to achieve the necessary treatment roll-out to cover the country's urgent needs, they expressed a belief that ARVs would become more readily accessible and affordable over time. And while the group was uncertain as to the complete eradication of HIV/AIDS, they were hopeful that their efforts would contribute towards the dissolution of stigma so that HIV-positive South Africans could live freely without fear. Although I selected six specific portraits to explore in my analysis - Gugu, Phindile, Bhekisisa, Betty, Nontyatyambo and Lindiwe - all seventeen of these individuals and their self-portraits make key contributions in the global visual expression of living with HIV/AIDS. There is no doubt that there is a continuous shift in the representation of people living with HIV/AIDS. The *Through Positive Eyes* arts initiative marks a point on this ever-changing trajectory and through this dissertation, I hope to contribute to greater public understanding of stigma and the way the arts have the power to contribute to this ever-changing, ever-evolving trajectory. By presenting alternative forms of representation of individuals living with HIV/AIDS, this thesis demonstrates how the arts not only challenge our understanding of stigma but transform it. The activists who began to contest representations in the 1980s left a legacy to those of us contributing to this shift of representation thirty years later. The *Make Art/Stop AIDS* project in conjunction with the *Through Positive Eyes* initiative does not act on behalf of but facilitates for the HIV-positive individuals to represent themselves as the self-portraits will be utilised as an advocacy tool to lobby deeply engaged individuals and organisations like the United Nations and the Global Fund to enact greater accessibility and affordability of ARV treatment.

While my thesis necessarily has a conclusion, there is no conclusion to the challenges and complexities being experienced on a daily basis by people living with HIV/AIDS. The only conclusion will be once stigma is no longer relevant to the landscape of HIV/AIDS, and thereby any related discrimination will cease to exist. When there is equal access to human rights and this paradigm becomes the status quo, stigma will become irrelevant. With the UN Foundation's plan

for an AIDS-Free Generation by 2015, the goal to be achieved is – "zero infections," "zero deaths," and "zero discrimination."[288]

Figure 56: *ONE 2015 AIDS Quilt Panel 51125*[289]

My discovery of a patchwork quilt in memory of a cousin who is now gone nearly twenty years triggered my journey into engaging with the power of art in activism, awareness, and lobbying for universal accessibility and affordability of ARVs.

As an effect of the controversy over the disclosure of the status of children, which led the HIV-positive parents to engage in a discussion about supportive environments for their children, some positive and some negative, *TPE South Africa* is continuing its involvement in South Africa. With the help of Lefika La Phodiso, a local Johannesburg art therapy centre, a weekly 'safe space' came to life with four children engaging with various artistic materials and media. I hope to continue this work this year.

[288] "Children and AIDS: Fifth Stocktaking Report." UNAIDS and UNICEF. November 2010. [Online.] Available: http://www.unicef.org/media/files/Children_and_AIDS-Fifth_Stocktaking_Report_2010_111610.pdf. [1 February 2012].
[289] Make your own at www.**2015**quilt.com/.

I end with my own creation for the One Campaign's 2015 patchwork quilt (see the image above). – having an AIDS-Free Generation by 2015 may be optimistic, but I would rather err on the side of optimism. It is in the vein of this optimism that I re-iterate Crimp, 'art does have the power to save lives'. Ultimately, it is in the next generation that self-reflection and self-worth will hopefully be fostered earlier and stigma will not be as embedded into the psyche of the individual – then and only then when the trans-generational trauma of HIV/AIDS is liberated and disclosure faces no consequences can there be a genuine change in the lens of stigma.

REFERENCES

"About the Quilt." *The Names Project*. 2011. Web. Available: http://www.aidsquilt.org/about.htm. [1 February 2012].

Achebe, Chinua. "An Image of Africa: Racism in Conrad's Heart of Darkness." In W. *W. Norton & Company's Critical Edition of Joseph Conrad's Heart of Darkness*. 1988.

"AIDS Epidemic Update 2004." *UNAIDS/WHO: Joint UN Programme on HIV/AIDS*. December 2004. Web. Available: http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2004/2004_epiupdate_en.pdf. [October 2011].

"ARVS Open To All: Motlanthle." *Sunday Times Live*. 12 August 2011. Web. Available: http://www.timeslive.co.za/local/2011/08/12/arvs-open-to-all-motlanthe. [1 February 2012].

"Background Note: South Africa." U.*S. Department of State, Bureau of African Affairs*. 30 January 2012. Web. Available: http://www.state.gov/r/pa/ei/bgn/2898.htm. [1 February 2012]

Banks, Daniel. "Unperforming 'race': Strategies for Reimagining Identity." *A Boal Companion: Dialogues on Theatre and Cultural Politics*. Eds. Jan Cohen-Cruz and Mady Schutzman. New York and London: Routledge, 2006.

Barthes, Roland. *Camera Lucida: Reflections on Photography*. Transl. by Richard Howard. London: Vintage Books, 2000. [Originally published in 1980.]

Bates, Annwen. "Wearing the T-shirt: an exploration of the ideological underpinnings of visual representations of the African body with HIV or AIDS." *African Journal of AIDS Research* 6.1 (2007): 67-78.

Berger, John. *Ways of Seeing*. London: Penguin Books, 2008. (First Edition 1972).

Biko, Steve. "The Definition of Black Consciousness." *I write what I like*. Northlands: Picaor Africa, 2004. [Originally published in 1978.]

Biko, Steve. "We Blacks." *I write what I like*. Northlands: Picador Africa, 2004. (Originally published 1978.)

Booker, Salih and Minter, William. "Global Apartheid." *The Nation*. 21 June 2001. Web. Available: http://www.thenation.com/print/article/global-apartheid. [1 February 2012].

Boon, Richard and Plastow, Jane. "Introduction." *Theatre and Empowerment: Community Drama on the World Stage*. Eds. Richard Boon and Jane Plastow. Cambridge: Cambridge University Press, 2004.

"Brothers for Life." n.d. Web. Available: http://www.genderjustice.org.za/index.php/projects/brothers-for-life. [1 February 2012].

Cameron, Edwin. *Witness to AIDS*. Cape Town: Tafelberg Publishers Limited, 2005.

Crimp, Douglas. "AIDS: Cultural Analysis/Cultural Activism." AIDS: Cultural Analysis/Cultural Activism. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988.

Das, Veena. "Language and Body: Transactions in the Construction of Pain." Kleiman, Arthur, Veena Das, and Margaret Lock. Eds. *Social Suffering*. Berkeley: University of California Press, 1997.

Deacon, Harriet. "Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature." *Journal of Community and Applied Social Pscyhology* 16.6 (2006): 418-425. Web. [1 February 2012].

Deacon, Harriet. "Unravelling the Contexts of Stigma: From Internalisation to Resistance to Change." *Journal of Community and Applied Social Psychology* 16.6 (2006): 411-417.

Evans, Sally. "SA can't live without cellphones." *Sunday Times Live*. 10 March 2010. Web. Available: http://www.timeslive.co.za/business/article348468.ece/SA-cant-live-without-cellphones. [1 February 2012]

Farmer, Paul. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press, 1992.

Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berekeley: University of California Press, 2005.

Field, Sean. "'What can I do when the interviewee cries?', Oral History Strategies for Containment and Regeneration." *Oral History in Contemporary South Africa*. Ed. Phillip Denis. Durban: Kwazulu-Natal University Press, 2008.

Flores, William V. and Rita Benmayor. "Introduction: Constructing Cultural Citizenship." *Latino Cultural Citizenship*. Flores, William V, and Benmayor, Rita. Eds. Boston: Beacon Press, 1998.

Frolich, Janet. "The impact of AIDS on the community." Karim. S. S., Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008.

"Gender-based violence." *UNICEF South Africa – HIV and AIDS*. n.d. Web. Available: http://www.unicef.org/southafrica/hiv_aids_729.html. [1 February 2012]

Gere, David. "About." *Through Positive Eyes*. 2008. Web. Available: http://throughpositiveeyes.org/about. [1 February 2012].

Gere, David. "Drama for Life Festival Keynote." University of Witswatrsrand. August 2011. Lecture.

Gere, David. "Gideon and TPE and Photos." Message to Hanni Ress. November 2011. Email.

Gere, David and Mendel, Gideon. HIV-*Positive in Los Angeles: Twelve Stories*. February 2007. Web. Available: http://artsci.ucla.edu/hivla/. [1 February 2012].

Gilman, Sander L. *Health and Illness: Images of Difference*. London: Reaktion Books, 1995.

Godby, Michael. "Aesthetics and Activism." Art South Africa 5.2 (2007): 1-6. Web. Available: http://www.artsouthafrica.com/?article=66. [16 November 2011].

Goffman, Erving. "Preface." *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963.

Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Middlesex: Penguin Book, 1963.

Gray, A. *An Introduction to the Therapeutic Frame*. London: Routledge, 1994.

Green, Gill and Sobo, Elisa J. *The Endangered Self: Managing the Social Risks of HIV*. London and New York: Routledge, 2000.

Griffin, Gabriele. "Introduction." *Representations of HIV/AIDS: visibility blue/s*. Manchester: Manchester University Press, 2000.

Grover, Jan Zita. "AIDS: Keywords." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988.

Kaleeba, Noerine. "Introduction." Mendel, Gideon. *A Broken Landscape*. Barcelona: Art Blume with ActionAids, 2001.

Karim, Quarrisha Abdool. "Heterosexual transmission of HIV – the importance of a gendered perspective in HIV prevention." Karim, S. S. Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008.

Lacan, Jacques. "The mirror stage as formative of the function of the I as revealed in psychoanalytic experience." *Ecrits*. Transl. by Alan Sheridan. London: Tavistock Publications Limited, 1977. [Originally published in 1949]

Leader, Darian and Groves, Judy. *Introducing Lacan*. Ed. Richard Appignanesi. Cambridge: Icon Books, 2000. [Originally published in 1996.]

Marinovich, Greg and Silva, Joao. *The Bang-Bang Club: Snapshots from a Hidden War*. London: Arrow Books, 2000.

Mayer, Ruth. "Don't Touch! Africa is a Virus!" *Artificial Africas: Colonial Images*. Dartmouth: University Press of New England, 2002.

Mbembe, Achille. *On the Postcolony*. Berkeley: University of California Press, 2001.

Mendel, Gideon. "Living with AIDS." *National Geographic: Africa, Whatever You Thought / Think Again*. September 2005. 66-73.

Mendel, Gideon. In Shana Ting Lipton's "Beyond the Statistics: Student art project at UCLA puts human face on HIV/AIDS." *Los Angeles Sunday Times*, 1 March 2007. E10-E11. [1 February 2012].

Mhlongo, Dr. Sam. "So, Only African Have Sex?" *New African*. September 2001. 35. [Found in Julia Stewart's *Quotable Africa*. London: Penguin Books, 2004. 199.]

"Mirror stage." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Mirror_stage. [13 October 2010.]. 2.

Moon, Catherine Hyland. *Studio Art Therapy: Cultivating the Artist Identity in the Art Therapist*. London: Jessica Kingsley Publishers, 2002.

Msomi, Sinothile and Shilaho, Westen. "Racism Still a Threat to South Africa." The Centre for the Study of Violence and Reconciliation. c2008. Web. Available: http://www.csvr.org.za/index.php?option=com_content&view=article&id=2262:racism-still-a-threat-to-south-africas-democracy&catid=139:media-articles&Itemid=37. [1 February 2012].

Myburgh, James. "In the beginning there was Virodene," Eds. Cullinan, Kerry and Thom, Anso, *The Virus, Vitamins & Vegetables: The South African HIV/AIDS Mystery*. Auckland Park: Jacana Media, 2009.

Navarre, Max. "Fighting the Victim Label." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge: The MIT Press, 1988.

Nitsun, Morris. "Early Development: Linking the Individual and the Group." *Group Analysis*. Vol. 22. London: SAGE, 1989.

Patton, Cindy. *Inventing AIDS*. New York and London: Routledge, 1990.

Peters, Reverend A. Stephen. "HIV/AIDS: Is It God's Judgment?: A Christian View of Faith, Hope and Love." *The Body: The Complete HIV/AIDS Resource*. 1994. Web. Available: Http://www.thebody.com/content/art5908.html. [1 February 2012]

"Photovoice." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Photovoice. [1 February 2012].

Price, Monroe E. *Shattered Mirrors: Our Search for Identity and Community in the AIDS Era*. Cambridge: Harvard University Press, 1989.

Said, Edward. *Orientalism*. New York: Vintage Books, 1979.

"Shosholoza." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Shosholoza. [24 October 2010].

Siopis, Penny. *Not Alone* Catalogue. Web. Available: http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf. [1 February 2012].

Slim, M. and Thompson, P. *Listening for a Change: Oral Testimony and Development*. London: PANOS, 1993.

Sontag, Susan. *AIDS and Its Metaphors*. London: Penguin Books, 1990. [First published 1989].

Sontag, Susan. *On Photography*. London: Penguin Books, 2008. 3. [Originally published in 1977].

"South Africa: Epidemiological Fact Sheet on HIV and AIDS." UN AIDS/WHO. Web. Available: http://apps.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_ZA.pdf. September 2008.

"South Africa: Treatment and Care." UNSource: Country Progress. Web. Available: http://www.unaids.org/en/regionscountries/countries/southafrica/. 2010.

Spivak, Gayatri Chakravorty. "Can the Subaltern Speak?" *Marxism and the Interpretation of Culture*. Eds. Cary Nelson and Lawrence Grossberg. London: Macmillan, 1988.

Spivak, Gayatri Chakravorty. "Gayatri Spivak: The Trajectory of the Subaltern in my Work." *Voices*. University of California, Santa Barbara. September 2004 Lecture. [Humanities – Show ID 8840]. Web. Available: http://www.youtube.com/watch?v=2ZHH4ALRFHw. [1 February 2012].

Tagg, John. *The Burden of Representation: Essays on Photographies and Histories*. London: The Macmillan Press, 1988.

Thomas, Kylie. "Selling Sorrow: testimony, representation and images of HIV-positive South African women." *Social Dynamics* 34.2 (September 2008): 216-226.

Treichler, Paula. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification." *AIDS: Cultural Analysis/Cultural Activism*. Ed. Douglas Crimp. Cambridge, Mass.: MIT Press, 1988.

Treichler, Paula A. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press, 1999.

Treichler, Paula A. "Prologue." *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press, 1999.

Tutu, Archbishop Desmond. "Foreword." Williamson, Sue. *Resistance Art in South Africa: Reissue of the Classic*. Cape Town: Double Storey Books, 2004. [Originally published in 1989].

"Ubuntu." *Wikipedia*. Web. Available: http://en.wikipedia.org/wiki/Ubuntu_(philosophy). [5 September 2012].

Wang, Carol. "Photovoice: A Participatory Action Research Strategy Applied to Women's Health." *Journal of Women's Health* 8.2 (1999): 185-192. Web. [1 February 2012].

wa Thiong'o, Ngũgĩ. "Introduction." *Decolonising the Mind: The Politics of Language in African Literature*. Oxford: James Currey, 1986.

wa Thiong'o, Ngũgĩ. "The Language of African Literature." *Decolonising the Mind: The Politics of African Literature*. Oxford: James Currey, 1986.

wa Thiong'o, Ngũgĩ. "The Quest for Relevance." *Decolonising the Mind: The Politics of Language in African Literature*. Oxford: James Currey, 1986.

Watney, Simon. "An Introduction." *Taking Liberties: AIDS and Cultural Politics*. Eds. Erica Carter and Simon Watney. London: Serpents Tale, 1989.

Watney, Simon. "Photography and AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. [Essay first published 1988.]

Watney, Simon. "Mission Positions: AIDS, 'Africa,' and race." *Selection of Essays*. Durham: Duke University Press, 1994. [Essay originally published in 1989.]

Watney, Simon. "The Spectacle of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. 46-59. [Essay originally published 1988.]

Watney, Simon. "The Subject of AIDS." *Selection of Essays*. Durham: Duke University Press, 1994. [Essay first published 1987.]

Whiteside, Alan and Sunter, Clem. *AIDS: The Challenge for South Africa*. Cape Town: Human & Rousseau and Tafelberg Publishers, 2000.

Williamson, Judith. "Every Virus Tells A Story: The Meaning of HIV and AIDS." *Taking Liberties: AIDS and Cultural Politics*. Eds. Erica Carter and Simon Watney. London: Serpents Tail, 1989.

Williamson, Sue. "Preface to the Re-issue." *Resistance Art in South Africa: Reissue of the Classic*. Cape Town: Double Storey Books, 2004. [Originally published in 1989].

Williamson, Sue. *South African Art Now*. Collins Design, 2009.

Wilson, Douglas and Fairall, Lara. "Challenges in managing AIDS in South Africa." Karim, S. S. Abdool and Karim, Q. Abdool. Eds. *HIV/AIDS in South Africa*. Cambridge: Cambridge University Press, 2008.

Wilson, Phil. *HIV-Positive in Los Angeles: Twelve Stories*. 2007. Web. Available: http://artsci.ucla.edu/hivla/phill/index.html. [1 February 2012].

Yow, V. *Recording Oral History, A Practical Guide for Social Scientists*. London: SAGE, 1994.

Zamora, Pedro. *LGBT History Month*. 2011. Web. Available: http://www.lgbthistorymonth.com/pedro-zamora. [1 February 2012].

IMAGE REFERENCES

Artist Unknown. *African AIDS Patient*. n.d. Web. Available: http://scrapetv.com/News/News%20Pages/Health/Pages/AIDS-loses-lustre-after-being-exposed-as-a-bully-Scrape-TV-The-World-on-your-side.html. [1 February 2012].

Artist Unknown. *HIV-Positive T-Shirts in Kolkata.* 2004. UCLA Art|Global Health Center.

Artist Unknown. *Keiskamma Altarpiece.* C2007. UCLA Art|Global Health Center.

Artist Unknown. *Komal Gandhar Dance Group.* 2004. UCLA Art|Global Health Center.

Artist Unknown. *Late Gugu Dlamini.* nd. Beat It. Web. Available: http://www.beatit.co.za/archive-people/gugu-dlamini. [1 February 2012].

Betty. *Betty in the Cushions*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Betty. *Betty in Green*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Betty. *Betty's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Betty. *Turquoise Gown Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

"Beyond the Statistics." By Shana Tang Liption. *Los Angeles Sunday Times*. 1 March 2007. E10-E11.

Bhekesisa. *Bhekesisa's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Burial Site*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Cemetery*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Family Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Kissing Daddy*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Kissing Mama*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Bhekesisa. *Soccer Player*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Burman, Marie. *Memorial to Steve Gilden.* c1990s. The Names Project Foundation. Web. Available: http://www.aidsquilt.org/view-the-quilt/search-the-quilt. [1 February 2012].

Elo. *Silence = Death*. Weblog entry. *Great Political Posters That Changed U.S. History.* Think Smart Designs Blog. Available: http://thinksmartdesigns.blogspot.com/2010/06/great-political-posters-that-changed-us.html., June 2010. Web. [1 February 2012].

Fierce, Whitney. *Pamela Coffey in a Favourite Thinking Spot*. 2007. UCLA Art|Global Health Center.

Fierce, Whitney. *Pamela Coffey in her Kitchen*. 2007. UCLA Art|Global Health Center.

Gordon, Bobby. *Edwin Cameron and Mandisa Dlamini*. 2010. Drama for Life. Web. Available: http://www.dramaforlife.co.za/index.php/gallery/image_full/188/. [1 February 2012].

Gugu. *Broken Cacti*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Glasses*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Gugu's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Pile of Stones*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Plastic Bottle Collector*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Rubbish Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Gugu. *Water Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Lindiwe. *Closed Hands for Strength*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Lindiwe. *Dumped Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Lindiwe. *Hand Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Lindiwe. *Lindiwe's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Lindiwe. *Open Hands for Freedom*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Magwa, Langa. *Uphondo (The Vice of the Affected and Infected)*. 2007. UCLA Art|Global Health Center. Collection: Durban Art Gallery.

Mendel, Gideon. *Florence Kumunhyu, Iganga, Uganda*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 176-77.

Mendel, Gideon. *Funerals, Copperbelt, Zambia*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 94-95.

Mendel, Gideon. *The Harsh Divide.* 2003. Drama for Life. Web. Available: http://www.gideonmendel.com/. [1 February 2012].

Mendel, Gideon. *Hospital, KwaZulu-Natal, South Africa*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001. 48-49.

Mendel, Gideon. *Treatment Action Campaign, Durban, South Africa – World AIDS Day 2000*. In Gideon Mendel's *A Broken Landscape*. Barcelona: Art Blume, 2001.

Phindile. *Envelope*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Phindile. *Phindile and Fiancee*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Phindile. *Phindile's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Nontyatyambo. *Flying Birds*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Nontyatyambo. *In Love*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Nontyatyambo. *Nontyatyambo's Self-Portrait*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Nontyatyambo. *Playing Outside*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Nontyatyambo. *Respect Series*. March 2010. *Through Positive Eyes.* UCLA Art|Global Health Center.

Reininger, Alon. *Homosexual AIDS Patient.* 31 May 2011. Contact Press Images. Web. Available: http://www.nytimes.com/2011/05/31/health/31aids.html?pagewanted=all. [1 February 2012].

Shapiro, Jonathan (aka Zapiro). *Virodene, Dr. Rath and HIV*. Cartoon. *Not Alone Catalogue.* Web. Available: http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf. [1 February 2012]. 2005.

Siopis, Penny. *AIDS Baby Africa*. 1996. *Not Alone Catalogue.* Web. Available: http://www.makeartstopaids.org/pdf/notAloneCatalogueForWeb.pdf. [1 February 2012].

INTERVIEW REFERENCES

Betty. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010.

Bhekesisa. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 12 March 2010.

Coffey, Pamela. Personal Interview for *HIV-Positive in Los Angeles: Twelve Stories*. February 2007.

Gladys. Group Discussion in *Through Positive Eyes South Africa*. Johannesburg: Make Art/Stop AIDS. 2 March 2010.

Group Discussion in *Through Positive Eyes South Africa*. Johannesburg: Make Art/Stop AIDS. 2 March 2010.

Gugu. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010.

Lindiwe. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010.

Ludick. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 11 March 2010.

Nontyatyambo. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 9 March 2010.

Phindile. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010.

Pleasure. Personal Interview for *Through Positive Eyes South Africa*.. Johannesburg: Make Art/Stop AIDS. 10 March 2010.